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Living with a memory-impaired spouse: (Re)cognizing the experience, (re)storying support

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LIVING WITH A MEMORY-IMPAIRED SPOUSE:

(RE)COGNIZING THE EXPERIENCE, (RE)STORYING SUPPORT

by

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ABSTRACT

Dementia, of which Alzheimer's Disease is the most common, results in severe cognitive deterioration and the victim will become increasingly unable to manage his or her own care needs. Someone else will be required to take on responsibility for attending to these needs. If married, the person most likely to be implicated is the spouse. Research has documented that these spouses are at high risk in the caregiving role, yet are the least likely of all caregivers to utilize formal support. To date, this low use of services has been poorly understood despite concerns that without assistance, these spouses may jeopardize both their own health and well-being *and* the quality of care being provided to their partner. The goal of this study was to better understand the personal experience of living with a memory-impaired partner and to explore how this experience interfaced with the use of formal support services.

Fourteen spouses whose partners were suffering from deteriorating cognitive disorders were interviewed between one and three times. Participants were recruited who had displayed some reluctance to utilize the formal support services that service providers had suggested might be beneficial or who had strong opinions regarding the role of formal support services in their personal experience. Understanding was generated using an in-depth, unstructured interview focused on exploring the participant's `story' about his or her experience in general and formal service use in particular.

What clearly emerged from this study was the complexity associated with the decision to utilize services. Using participants' personal stories, I developed a conceptual model to organize understanding. This model identifies and explicates the importance of particular discourses for positioning the meaning associated with service use. I suggest that there are prevailing `story-lines' or discourses that provide a set of assumptions and beliefs that are used by the individual to construct one's own personal understanding about one's actions and possible choices. Specifically, I identify four story-lines which exert influence on meaning making. These include two story-lines which compete to locate the responsibility of caring on a continuum between a private and a societal responsibility. I call this continuum the site for locating the caring activities. Intersecting with this `site' is another `site' that positions one's psychological orientation. This site, or continuum, has two story-lines associated with each of it's endpoints; these compete to establish the importance of a sense of self that is grounded in values of self-sufficiency as opposed to relational connection.

Using this conceptual model, I suggest that practically, this means that the well spouse will potentially be hearing four different story-lines for sense-making. Some of these story-lines will fit well together but others will conflict. This leads to contradictory and inconsistent `interpretive repertoires' for making sense of service use. The goal then becomes to determine where an individual is positioned in the quadrant created by these intersecting `sites' in order to assess which story-lines are most influential for assigning meaning to the use of formal service for that individual. By understanding this, service providers can begin to untangle and challenge the meanings that will be associated with service use by that individual.

Moreover, examining the participant's experiences using this conceptual model highlights the ways that practices associated with providing support may be propagating story-lines that are not conducive to the use of services and are oppressive to the well spouse. Strategies for promoting more responsive, and less oppressive `support' are suggested.

ACKNOWLEDGEMENTS

Since its inception about three years ago, there have been many moments of despair as I wondered whether I would ever finish this project. One of my techniques for re-motivating myself was to mentally begin to write this acknowledgement. As soon as I began to put names to the people who have supported me, I would find myself re-energized; I did not want them to feel that their efforts on my behalf and their belief in me had been misplaced. Now that it is time to publicly acknowledge these people, I find myself lost for words. So many people have supported, encouraged and assisted me during this `journey'.

First, I would like to thank the four members who formed my advisory committee: Dr. Jane Aronson, Dr. Martha Laurence (chair), Dr. Judith Levene, and Dr. Amy Rossiter. All four of these women have consistently provided intellectual stimulation and direction while simultaneously being emotionally responsive and supportive.

Additionally, I want to acknowledge the importance of my family in my journey. My mother, Kathleen Dort O'Connor, a pioneer in her own right, has always encouraged me to pursue my dreams and has tirelessly acted as both a sounding board for my ideas and an editor; I have benefitted enormously from her 'way with words' and emotional/intellectual support. My father, Roderick O'Connor, (who claimed he didn't fully comprehend what I was doing) actively supported me and my work unconditionally. My two sisters Cherie O'Connor and Shannon O'Connor who, despite

their own hectic lives, have always managed to be there whenever I needed a shoulder to lean on; in addition to their strong emotional support, they and their respective partners, John Stinson and Noel Paterson, have provided technical guidance and support, and food!

Several of my friends have played an important part in this project. Appreciation goes to: Lise Beauchesne, my partner in the doctoral program, for her hours of thoughtful insight, jelly-beans and shared emotions; Jackie Boyle; John and Alice Kuffel; and my colleague, Brian O'Neill, for keeping me grounded during the past two years.

Most importantly, I want to acknowledge my gratitude to the fourteen individuals who generously shared their time and expertise with me. Without them, there would be no project. Moreover, I recognize that this project would not have taken place without the valuable assistance of a number of service providers who helped me access potential participants; to preserve the anonymity of the participants these important individuals will remain unnamed but my appreciation will not.

Finally, I want to say a special thank-you to the people who lived with this project on a day-to-day basis for such a long time - whether they liked it or not! To Ken Holdren, for his technical wizardry and support, and to my two sons, Taylor and Ryan Holdren - you mean the world to me guys!

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PREFACE

I am a gerontological Social Worker with over ten years of clinical experience in the field of Aging. When I began this practice in early 1980, the myth of senility as an expectable outcome of the aging process was only beginning to be dispelled among the general public. The misconception was being replaced with the recognition that serious memory loss was related to a 'disease' or illness that could eventually be fatal. Alzheimer's Disease, although only one potential cause, became a household word. Simultaneously, the profound impact that this 'disease' process had on other family members was attaining increased attention. Mace and Rabins (1981) published their classic The 36 Hour Day, and Kapust (1982) referenced the family's plight as an 'ongoing funeral'. There was growing recognition of the family as the 'hidden victims' (Zarit, Orr and Zarit, 1985) .

Interest in the family increased even more when research began to document their role in diminishing the risk of institutionalization for the 'patient'. Particularly given the trend toward 'community care' the family had clear value. (In fact some have skeptically proclaimed that community care is simply a euphemism *for* family care!) The need to support the efforts of the family was identified and sanctioned. Formal support programs, consisting predominantly of homesupport services, temporary respite services and (usually group) counseling, were established.

As a clinical Social Worker working with family members of dementia victims it became increasingly apparent to me that service availability did not insure utilization. Informal conversations with other professional colleagues revealed that they shared this

'insight'. Some families' members, regardless of how distressed they might feel attempting to meet the needs of their impaired relative, were simply not receptive to formal intervention. Spousal caregivers in particular seemed to be less likely to readily take advantage of available support services.

Working with these individuals could feel extremely distressing. Often I found myself in situations where I could see the supposedly 'well' partner physically and mentally deteriorating before my eyes. Not uncommonly, I was aware that the situation was becoming so desperate that at least one of the partner's was becoming physically aggressive with the other. I wanted to help but felt so impotent. I listened to other community professionals also voice their frustration at having to 'close cases' that they knew were tenuous but in which they had no mandate to remain involved because the 'well' partner was identifying no need for involvement.

I turned to the literature for assistance. Research on the use of services by caregivers was scant but did support my impression that this group, particularly spousal caregivers, did not tend to use services. Only superficial, if any, explanation was offered regarding 'why'. A number of researchers supported my perception that this was an important area which required further exploration.

This thesis then represents my quest to better understand the limited use of services by spouses who are living with a memory-impaired partner. Reflecting my position at the time, I began with an exploration of the literature focussed on the general question 'why are caregiver's resistant to using services?' What quickly became apparent to me were the set of assumptions that were blinding my vision. For example, this question presumes the

existence of a `caregiver' and is based on the premise that services are necessarily useful and hence there is something wrong with the `caregiver' who won't use them. None of these assumptions were born out when I began to critically read the literature. Rather, as demonstrated in Chapter 1, the literature reveals an inadequate conception of the experience of living with a memory-impaired spouse and an even more limited appreciation of how that experience interfaces with the use of services. This understanding of the literature was used to situate my research.

Specifically, at this point my research interest broadened as I began to recognize the importance of developing a context in which to position the experience of the well partner living with a memory-impaired partner. Two new assumptions replaced my earlier perspective. First, I assumed that living with a memory-impaired partner was a complicated experience that was not being adequately captured by the conventional focus on stress that predominated the literature. In fact, this focus on stress provided a simplistic reduction of the experience, fostered a unitary focus on the individual family member as the problem, and led 'naturally' to the conclusion that there was something wrong with the individual who did not take steps to reduce his or her stress level. In contrast, acknowledging the complexity of the experience alerted me to the multiplicity of needs and divergent meanings that could be associated with service use. The possibility was raised that there could be good reasons why spouses chose not to use available formal support services. The second assumption I brought into this project is that the individual interpretations of the experience could only be fully understood when contextualized within the socio-political environment which produced them. This meant that I wanted to listen beyond the individual experience to

uncover the implicit assumptions that were being used to make meaning.

My goal for this research was to begin to reconceptualize the experience of living with a memory-impaired partner in order to deepen understanding of the meanings that could be associated with service use. In particular, I wanted to broaden insight regarding how the experience of living with a memory-impaired partner interfaced with the use of formal services. This thesis documents this journey.

As already noted, Chapter 1 presents an overview of the literature that I used to situate my research focus. The purpose of this presentation is to make explicit the knowledge and understanding that I used to position my approach to this project. It provides a 'snapshot' of what I 'knew' when I started and helps to contextualize where this specific project fits with the general body of research in this area.

Chapter 2 documents my research process. It provides the grounding for understanding what I did and why I made particular choices in the research design and analysis. I do want to note that retrospectively, the path looks considerably more straightforward and internally consistent than it often felt while I was actually taking the journey! For this journey has not only been about exploring the experiences of spouses living with a memory-impaired partner, it has also represents my personal quest to understand and position myself within the vast arrays of qualitative methodologies.

From the first interview, I was excited by this project and felt that I was gaining important insight. However, when it was time to begin formally writing about what I was learning, I struggled for months to find a way that would allow me to feel 'true' to the stories of the participants. I wanted to capture as much of the `whole' story as I could, to

convey the complexity and intensity of the experience. I didn't want to fragment the stories into neat categories that belied the intricacies and interconnections. Moreover, I wanted these experiences to be associated with unique individuals and not simply generic 'caregivers'. In an effort to accomplish this, I decided to develop individual case studies based on the stories of four selected participants. Using the analytic process of discourse analysis I 'reconstructed' each of their individual experiences in order to develop a contextualized understanding of each of their personal stories. These case studies are presented in chapters 3 through 6. They are presented in the order that they were developed and illustrate my emerging understanding: Each of these participants' stories had triggered my awareness about a particular insight into how the experience of living with a memory impaired partner interfaced with the use of formal support.

While constructing these case studies, I continually questioned how my understanding of each individual participant helped to develop broader insight regarding the experience. I contrasted and compared aspects of each person's story to highlight similarities and differences. By the time I finished writing the four case studies I had developed a preliminary conceptual frame for examining the experiences of the other participants. To refine these ideas, I returned my focus to these remaining transcripts and my earlier analytic notes and ideas. Chapter 7 presents the conceptual framework that emerged through this process. This framework suggests that the well spouse has at least four story-lines - each with its own underlying set of assumptions, beliefs and practices - that can be used for making sense of his or her experience. This chapter examines these four story-lines and explores how each one influences the meaning associated with service use.

So what? In Chapter 8, I return to my starting position as a clinical Social Worker to explore how this new understanding can be applied to practice. Referencing each story-line I develop specific strategies for promoting more effective support for spouses whose partners are suffering from deteriorating cognitive abilities. My intent in this chapter was to explicate specific ways that this new understanding has helped me to reconceptualize my practice. Writing this chapter was particularly exciting for me because I was confronted with the recognition of how my ideas of practice had been dramatically changed by this study. Specifically, in this section I have tried to develop ideas which "treat" a situation that is problematic rather than problematizing the individual "caregiver"; this approach recognizes the Social Worker's responsibility to respond at an individual level but it also advocates the need to redress societal inequities and forms of oppression. In contrast, consistent with most Social Work practice models - including models such as the Strength perspective and the ecological models - my earlier work paid little attention to the hidden assumptions, beliefs and practices through which people's actions were constructed.

Through the process of completing this study then, I have arrived at a different way of understanding the experience of living with a memory-impaired partner; I have (re)cognized this experience and (re)storied the notion of support. My ideas about effective practice with this population have changed dramatically as a result. I hope my story about this process will influence others as effectively as the stories told to me by the fourteen individuals who participated in this study effected me.

CHAPTER 1

SITUATING THIS STUDY

INTRODUCTION

An estimated 6% of the elderly population in Canada suffer from dementia - a progressive, irreversible organic brain disorder (McEwan, Donnelly, Robertson and Hertzma, 1991). Alzheimer's Disease and Multi-infarct dementia are the two most prevalent causes. Gradually deteriorating memory will be the most apparent symptom, but other capacities such as abstract thinking, judgment, and verbal abilities, will also be affected. There may be personality changes, and psychiatric/behavioral problems such as hallucinations, agitation, and suspiciousness, are not uncommon. Initially the victim will look well, but as the disease progresses, physical functioning will also decline. With time, the individual's ability to manage his/her own care will be so compromised, that s/he will be forced to depend upon someone else to have even the most basic of needs met.

If married, this `someone else' will most likely be the spouse (Cantor, 1983; Walker, 1991); one British study found 90% of married people requiring help were supported by their spouse (Bond, 1992). In comparison to other informal caregivers, a recent American survey revealed that approximately 36% of primary caregivers were spouses - 23% were wives and 13% were husbands (Stone, 1987) and a Canadian study reported that 32% of a randomly selected group of caregivers were spouses (Penning, 1995).

The assumption of this caregiving role is not typically the result of a conscious decision to care (Hooeyman, 1990), nor is it necessarily conditional upon feelings of affection or reciprocity (Walker, 1991; Horowitz and Shindelman, 1983). Oliver (1983) notes that spouses have the least choice of all in taking on the caregiving role - they have already agreed to care `for better or worse' - and findings by MacRae (1990) support this perception that at least for wives, caring for an ill spouse is seen as natural and necessary. The implications of the `selection' process, is the assumption of the caregiving role by family members, particularly spouses, who may or may not be suited to the role.

The value of the family caregiver is well recognized. It is estimated that between 85-90% of the care and support to seniors in the community is provided by the family (National Advisory Council on Aging, 1989). Brody (1985) determined that of the group of elderly receiving care from their families' in the United States, about 10% would have required institutionalization without this care: This would result in tripling the number of institutionalized elderly in the United States. Several other studies have demonstrated that the involvement of a family member, particularly a spouse, is a significant factor in predicting the chance for institutionalization (Carriere and Pelletier, 1995; Hanley et al., 1990; Shapiro and Tate, 1988; Palmore, 1976). In fact, with the dementia patient, the physical/emotional well-being of the caregiver appears to supersede even the physical/mental attributes of the impaired relative as a factor in the decision to institutionalize (Given et al., 1988; Zarit et al., 1986; Chenowith and Spencer, 1986; Deimling and Poulshock, 1985; Morycz, 1985).

That caregiving is stressful, at least for some, has been well established (Liebermaan

and Fisher, 1995; Zarit, 1989). The stress may be evidenced by increased susceptibility to physical health problems (Pratt et. al., 1985) as well as varying degrees of emotional distress and disturbances (Shulz, O'Brien, Bookwala and Fleissner, 1995; Jutras and Lavoie, 1995; Cantor, 1983; George and Gwyther, 1986). For example, research has documented increased incidents of depression among caregivers (Pagel et al., 1985; Coppel et. al., 1985; Haley et al., 1987; Gallagher et al., 1989), increased hostility (Anthony-Bergstone et al., 1988), poorer life satisfaction (George and Gwyther, 1986; Fengler and Goodrich, 1979), and increased perception of daily activities as hassles (Walstein, 1993). Problems with restrictions of social activities (George and Gwyther, 1986) including social isolation (Chenowith and Spencer, 1984) have also been identified.

Compared to other caregiving relationships, spousal caregivers have been identified as particularly vulnerable to emotional and/or physical problems related to the stress of the caregiving role (Barnes, Given and Given, 1992; Biegel, Sales and Schulz, 1991; Noelker, 1990; George and Gwyther, 1986; Gilhooly, 1984; Cantor, 1983). Furthermore, the literature suggests that wives experience even more distress than husbands fulfilling this role (Lieberman and Fisher, 1995; Gold, Fanz, Reis and Senneville, 1994; Karlin and Bell, 1992; Miller and Cafasso, 1992; Pruchno, Kleban, Michaels, and Dempsey, 1990; Barusch and Spaid, 1989; Pruchno and Resch, 1989; Fittings et al., 1986). For example, research has found that wives report significantly higher anxiety/depression scores (Lieberman and Fisher, 1995).

Recognizing the value of their support and the inherent risks associated with the caregiving role, the need to support family caregivers has been identified and clearly

sanctioned. In Ontario, the most recent affirmation of this commitment comes from the position paper, Redirection of Long-Term Care and Support Services in Ontario (1991). It targets family caregivers for increased support and proposes an expansion of formal support services directed at them. The assumption is that these support services will reduce the negative impact of caregiving, thereby enabling family caregivers to provide higher quality care for a longer duration. Without assistance, there is concern that family caregivers, particularly spouses, may jeopardize both their own health and well-being *and* the care that they are providing.

However, simply providing services does not insure utilization. One of the few studies using a randomly selected sample of caregivers revealed that less than 10% of caregivers were receiving any formal assistance (Stone et al., 1987). Compared to other caregivers, spousal caregivers are the least likely to use formal services (Wenger, 1991; Gonyea and Silverstein, 1991; Tennstedt et al., 1991; Johnson, 1983); in fact, Pruchno (1990) found that spousal caregivers were more reliant upon the impaired partner for help than on formal services! Furthermore, when the impaired partner is suffering from dementia, there is some research to suggest that these caregiving spouses may be particularly unlikely to use services. For example, Straw, O'Bryant and Meddaugh (1991) found that spouses caring for dementia victims were significantly less likely to report assistance from both formal and informal sources, even though they identified the presence of more needs than non-dementia caregivers.

How can the low utilization of support services by elderly spouses caring for a cognitively impaired partner, be understood?

REVIEW OF RELATED LITERATURE

A review of both the service utilization literature, and the massive body of research on informal caregivers, reveals significant gaps in our understanding of the issues surrounding the use of support services by the elderly in general, and caregivers in particular. In order to situate my research interest, the literature will be reviewed focused on two particular questions:

1. How has the utilization of formal support services by the elderly in general, and caregivers in particular, been examined and explained?

2. How have the service needs of spouses caring for a cognitively impaired partner been constructed? In other words, what are the underlying assumptions and/or understandings upon which supportive services for spousal caregivers have been developed?

Explaining service utilization

Research examining service utilization among the elderly and/or caregivers, has employed predominantly quantitative designs and can roughly be classified into two broad categories: exploratory/descriptive studies which have attempted to identify the factors that contribute to an individual's decision to use services; and studies which, using more sophisticated statistical procedures, have focused on developing predictive models for differentiating service users from non-users. The dominant conceptual framework used in

this research is a socio-cultural model proposed by Anderson and Newman (1973). This model organizes the individual factors associated with service utilization into predisposing, enabling and need factors. *Predisposing factors* include variables such as socio-demographics and health beliefs; *enabling factors* are the conditions that make services available to the individual such as income, service knowledge and social support; and *need factors* consider objective and subjective health status measures including functional limitations (Anderson and Newman, 1973) and stress effects resulting from caregiving (Penning, 1995; Bass and Noelker, 1987).

A major contribution of this research is that it exposes the complexity of the issues surrounding service utilization. Even elaborate models incorporating a full range of predisposing, enabling and need factors have explained only between 4.8% (Krout, 1983) and 39% (Wan and Arling, 1983) of the variance in service use among American elderly individuals and 36% (Chappell and Blandford, 1987) of the variance in the use of social services offered through Homecare in a Canadian sample. In other words, even in the most predictive model over 60% of the variance in service use has remained unexplained. While this amount of unexplained variance is not unusual in explanatory quantitative research, it still highlights the gaps in knowledge. As Wolinsky and Johnson (1991) conclude, `We do not really know what accounts for most health service use' (p. S3555). Rather, it is becoming increasingly apparent that the factors associated with service use are complicated and elusive.

Specifically, two general beliefs about service utilization, based on `common sense' assumptions, are being more closely scrutinized and found to be lacking. First, a common

reason cited for underutilization of services among the elderly in general, and caregivers in particular, regards limited awareness of, and/or access to, services. Research however, does not necessarily support this explanation (Collins, King, Given and Given, 1994; Gwyther, 1994; Caserta et al., 1987; Silverstein, 1984; Waxman et al., 1984; Krout, 1983). Certainly, knowledge of available services has been identified as an important variable in accounting for service use, but in isolation, it is inadequate (Wister, 1992; Gonyea and Silverstein, 1991; Spence, 1991). For example, in their research with caregivers, Montgomery and Borgatta (1989) noted that even with active recruitment, encouragement, and free access to service, almost one-third of the caregivers eligible for services did not use them. Similar difficulties have been reported by other researchers (e.g. Brody, 1992; Barusch and Spaid, 1991). Awareness and accessibility explanations do not offer a sufficiently comprehensive perspective for understanding service use; in other words, the low use of services by caregivers cannot be fully explained by inadequate knowledge of, or difficulty accessing, services.

Similarly, research has revealed that a simplistic understanding of `need' factors, is also inadequate for explaining service use. Specifically, although need factors have been identified as the most powerful predictors of service use (Chappell, 1994) a `lack of synchronization between issues of service use and need' has been noted (Wister, 1992). For example, one study found that spouses caring for dementia victims were significantly less likely to report assistance from formal sources, although they identified the presence of more needs than non-dementia caregivers (Straw et al., 1991). `Need' per se then, does not necessarily equate with the actual use of services.

Lack of a clear connection between need and service use may be related to deficient conceptions of `need'. In many studies, this concept has been limited to health and functional status measurements. Interestingly, a few studies have expanded the concept of need to include `perceived' need for service. For example, Coulton and Frost (1982) included both `perceived need' and `evaluated need' factors in their model predicting service utilization. They found that perceived need for service was a more important determinant than evaluated need based on health status and/or functional limitations. Similarly, other studies have identified `perceived need' as perhaps the most important factor affecting service use for both the elderly in general (Yeatts et al., 1992; Spence, 1991) and caregivers in particular (Caserta et al., 1987).

This response raises more questions than it answers. In particular, what does `perceived need' mean? How is it related to the concept of need based upon health, or functional limitations? In one of the few studies focused specifically on the use of services by caregivers, results reported by Caserta et al. (1987) indicate that caregivers attributing their non-use of services to perceived lack of need were significantly more likely to be spouses; spouses in this study reported slightly higher burden scores than other caregivers. Similarly, other researchers have noted a disparity between the researchers' and the participants' appraisal of the participant's need for service (e.g.. Spence, 1991; Moen, 1978). The research then, suggests the importance of the client's perception of need as a determinant of service use but does not explore how this perception of need is constituted.

Similarly limiting understanding, has been the historical tendency to examine service use from a discrete `either/or' perspective; respondents have been dichotomized as either

`users' or `non-users'. This perspective overlooks any process issues that may be associated with service use.

When the focus of understanding service use is confined specifically to caregivers, gaps in knowledge become especially pronounced. First, although seeking help has been identified as a `normative crisis' of caring for a cognitively impaired family member (Kuhn, 1990) little research has actually focused on the use of services by caregivers (Noelker, 1992). A recent review of the literature found only twelve research articles and presentations which included data on caregiver service utilization and most of these focused on caregivers who had actively sought out services (Rudin, 1994). Rather, research has focused predominantly on the use of services by the `patient', and in fact, with few exceptions (e.g.. Penning, 1995; Bass et al., 1992; 1987), has even ignored the potential relevance of the caregiver in the `patient's' use of services.

Certainly, there is some evidence to suggest that the family caregiver does have an important role in determining the use of service by the patient (Gwyther, 1994). For example, research has repeatedly found that being married and/or living with someone is predictive of less service use (Hanley and Weiner, 1991; Tennstedt, Sullivan, McKinlay and D'Agostino, 1990; Chappell and Blandford, 1987) suggesting that this person may have some impact on the decision to use services. Additionally, when caregiver factors were considered, Bass et al., (1987) found that caregiver need (defined in this study as the stress effects resulting from caregiving) was only a slightly weaker predictor of service use than were patient need factors in determining the use of in-home nursing or attendant services. Similarly, Penning (1995) found that need as defined by caregivers' perceptions of their

health emerged as significantly related to service use; interestingly however, in contrast to Bass et al., (1987) need as defined by caregiver burden was not a significant predictor. In other words, although preliminary research implies some relationship between family involvement and service use by the `patient', this research is quite limited and has not yet examined contradictory results.

The inadequate consideration of the impact of the caregiver on `patient' directed services is an important oversight. When the thrust of service is redirected from the `patient' as beneficiary to the caregiver the critical gaps in understanding become even more apparent. A number of questions regarding the use of services by caregivers' are left unaddressed. In particular, how is need for service constructed? Opie (1992) suggests that caregivers' occupy multiple locations, for example as consumer, mediator and co-worker. This places carers in a highly ambivalent position in relation to service provision and results in the identification of a number of contradictory positions within social policy and practice (p .19). Twigg (1989) also identifies the multiplicity of functions occupied by caregivers'. Presumably need would be defined differently depending upon the function. Furthermore, some research suggests that caregivers' may be less likely to take advantage of services when they are identified as the primary `target' (e.g.. Anthony-Bergstone, Gatz and Zarit, 1988). Is it implicit then, to the use of caregiver support services that the caregiver must identify with being `in need' (and therefore needy)? If so, how does this self perception come about? Alternatively, especially in a marital relationship, it would be expected that the reaction of the care recipient might impact the caregiver's perception of support (Noelker, 1992). This may be particularly important in the spousal relationship (Getzel, 1982). What role does the

`patient' have in determining the use of caregiver support services? The literature on service utilization to date, fails to ask, let alone answer, these questions.

Recognizing the superficiality of current understanding, a number of researchers have identified the need for more in-depth exploration of the dynamics and complex factors associated with services use for both the elderly in general (e.g.. Stoller, 1992; Krout, 1985, 1983; McKinley, 1972) and caregivers' in particular (e.g.. Rudin, 1994; Gonyea and Silverstein, 1991; Straw et al., 1991; Caserta et al., 1987). In particular, the relevance of individual attitudes and subjective meaning associated with service use for improving understanding of service utilization issues has been identified (King, Collins & Liken, 1995; Rudin, 1994; Hanley and Weiner, 1991; Pruchno, 1990; McCaslin, 1988; Harel, Noelker, and Blake, 1985; Gourash, 1978).

Conceptualizing Caregiver `Need'

A critical question remains - why do some caregivers' choose to use formal support services while others, sometimes despite being obviously overwhelmed, are less willing, or able, to use these services? How can their `needs' be better understood?

During the past fifteen years, an astoundingly large body of research has focused on promoting increased understanding of the issues and needs of family's caring for an elderly relative. The vast majority of this caregiving research has employed quantitative methods and been based upon a stress/burden framework for understanding (Farran et al, 1991). Although the theoretical foundation of this paradigm, as it has been applied in the gerontological literature, has been poorly articulated and diversely interpreted (Bond, 1992;

Pearlin et al., 1990), a simplistic general overview of it suggests the following: caregiving is stressful and can adversely affect various aspects of the caregiver's life; caregivers' cope with their situation in different ways; and mediating variables account for individual variation in caregiver reactions (Farran et al., 1991).

Research has then focused on attempting to understand the reactions of caregivers' by examining the influence of selected factors. Those that have been identified as important include: aspects of the patient's medical, functional, emotional or cognitive status such as duration of illness, prognosis, and nature of onset; the caregiver's health, socioeconomic status, social support and relationship to the patient; and appraisal and coping. Psychological factors, including preexisting emotional resources as mediating factors, have received, at best, strictly superficial attention (Biegel, Sales and Schulz, 1991).

The merit of this research for understanding the caregiving situation is twofold. First, it has promoted recognition of the value of informal care for maintaining disabled elderly in the community. Second, this body of literature clearly addresses the potential adverse effects that caring for an impaired relative can have on the family caregiver.

However, this perspective promotes only a severely limited understanding of the experience of `caregiving'. First, the vast majority of caregiver research has been predirected by the concept of `burden'. In fact, the measurement of burden is so prominent within the caregiving literature that it is identified as `the central feature of virtually all care-giving studies' (Biegel, Sales and Schulz, 1991 p.51). Despite this prevalence, however, there is a surprising lack of consistency in the understanding, use and measurement of this concept (Braithwaite, 1992, 1990; Zarit, 1992; Vitaliano, Young and Russo, 1991;

Gubrium, 1987; Montgomery, Gonyea and Hooyman, 1986; George and Gwyther, 1986; Poulshock and Diemling, 1984). For example, Braithwaite (1992) notes that:

> the term has covered everything from the debilities of the care-receiver and the feelings of the caregiver to the effects that caregiving has on the family from either a subjective or objective perspective (Braithwaite, 1992 p.4)

In other words, burden has been a popular but poorly understood term that has driven the caregiver research.

Given the lack of consensus in the conceptualization and measurement of burden, it is not surprising that the literature presents a confusing, inconsistent picture regarding the correlates and causes of burden (Schulz, 1991; Harper and Lund, 1990; Montgomery et al., 1985). Specifically, interpreting and comparing research findings is almost impossible because of the differential uses of this concept and the varied methods for measuring it within the literature.

However, more fundamental concerns with the focus on `burden' have surfaced. In particular, the focus on burden pre-directs the inquiry into the caregiver's reactions: When research questions are approached with a priori and/or common-sense assumptions, they may prevent researchers from entertaining alternate views and have sometimes led to unintended biases to confirm expectations (Montgomery and Borgatta, 1986 p.604). Within the caregiving literature, the focus on burden as a decontextualized, measurable construct has superseded an exploration of the experiences of the caregiver. As a result, understanding of the experience of caring has been seriously restricted because it assumes that hardships

convert automatically to burden and the range of other possible responses are ignored (Abel, 1990). For example, the potential importance of perceived meaning associated with the caregiving role (Neysmith, 1991; Abel, 1990) and the need to begin exploring more positive aspects of caregiving (Cohen et al., 1992; Farran et al., 1991) have been identified. " While stress and strain are certainly important feelings that a great many carers report, there are also far more complicated and contradictory feelings at work" (Ungerson, 1987 p.2).

Despite the problems associated with the concept, `burden' has played a significant role in program and policy development. Specifically, formal services were developed under the assumption that relieving some of the caregiver's daily responsibilities would result in less caregiver burden which would then increase the caregiver's capacity to function effectively in the situation and to maintain themselves in the caregiving role (Gallagher, 1985 p. 256). What this means then, is that the foundation upon which supportive services for caregivers' have been built is suspect; burden has yet to be defined in a way that adequately reflects service use.

Moreover, the adequacy of the conceptualization of social support has been questioned (Gottlieb, 1992; Noelker, 1992; Abel, 1990). For example, what is `supportive'? To date, relatively little is known about the "psychosocial and pathogenic processes" through which social support exerts its positive impact (Biegel, Sales and Schulz, 1991). It is only recently that some researchers (Kosberg and Cairl, 1991; Willoughby and Keating, 1991; Boss et al., 1990; Bass, Tausig and Noelker, 1988/89; Zarit et al., 1987; Montgomery et al., 1985) have begun to advocate the recognition that an appropriate match between the nature of the stressor and the type of assistance is required.

The essence of this appropriate match is not yet understood. Originally credited as a panacea for helping caregivers' cope, studies are only now beginning to reveal that supportive services may be useful for some caregivers, but have minimal, or even negative, effect with others. For example, Bass, Tausig and Noelker (1988/89) found that increased frequency in home support personnel was beneficial for the caregiver when the care-recipient was cognitively impaired but detrimental when the care-recipient was physically impaired. Similarly, Diemling (1991) demonstrated a differential effect of respite care on the caregiver depending upon the cognitive functioning of the care-recipient. Kosberg and Cairl (1991) isolated different service needs based on the caregiver's level of burden and competency - two concepts that they found to be unrelated. Spaid and Barusch (1991) highlighted the impact that *perception* of informal social support had on caregiver strain: adverse contact negatively affected strain while positive contact had no significant effect. Similarly, a qualitative study by Gubrium (1987) demonstrated the `it depends' quality of social support.

Considerably more research is required to begin individualizing needs and responses to formal supports. For example, the research currently fails to provide a foundation for developing clinical precision in differentiating between family caregivers' who will benefit from supplemental supports compared to those for whom other alternatives would be more appropriate. Moreover, little understanding currently exists to demonstrate how services attain the status as supportive - for example, is respite effective because of the break it affords or because the regular arrival of another person is a reminder to the care provider that s/he is not alone? This has not yet been explored. In other words, the research on caregiver support reveals an overly simplistic perception of formal support where the development of

clinical interventions and research on their effectiveness is still in the preliminary stages (Zarit et al., 1987). "It seems paradoxical that highly stressed caregivers' resist formal assistance, but the dynamics of caregiver strain and service-use are not well understood" (Noelker, 1992 p.51).

A methodological problem, consistent throughout the caregiving research, hinders this exploration; because of the general practice in the caregiving research to rely upon `convenience' samples of caregivers' for information, service needs are frequently being identified by those already connected in some way to the formal support system. Specifically, the majority of caregiver studies recruit volunteer caregivers' through the formal support network. For example, common methods of obtaining a sample include soliciting through support groups, community service providers and the Alzheimer's Society. The rationale for this practice is recognized. However, in light of the fact that the majority of caregivers' have no formal contact (Caserta et al., 1987), it is unlikely that these samples are in any way representative. In other words, service needs and involvement are being defined by individuals who have already been both willing and able to connect with the formal support service system. The opinions and reactions of individuals who have been less able or willing to make that connection are not reflected in this literature.

Another problem in the caregiving literature impedes understanding of the needs and experiences of an individual fulfilling the caregiving role. Specifically, what is a caregiver? Although caregiving is such a ubiquitous term that its meaning is taken for granted, a clear, consistent definition of the concept has not yet been employed within the caregiving literature. Depending upon the study, `caregiver' can include virtually anyone - from a distant

relative who telephones an institutionalized kin periodically, to the spousal caregiver putting in what Mace and Rabins (1981) so aptly describe as a `36 hour day'. Important variations such as the relationship, amount of care provided, the living arrangements of the care-recipient (lives with caregiver, alone in the community, or is institutionalized), and whether the individual has the main responsibility or augments the efforts of another (primary vs. secondary caregivers') are important distinctions that have not necessarily been made in the literature.

This lack of a clear, concise understanding poses problems in the interpretation of research findings (Malonebeach and Zarit, 1991; Dillehay and Sandys, 1990; Harper and Lund, 1990; Barer and Johnson, 1990). For example, there is growing recognition that gender, relationship and living arrangements are significant factors when attempting to understand a caregiver's reaction (Vitaliano et al., 1991; Noelker, 1990; Montgomery, Gonyea and Hooyman, 1986). Often however, these differences go unrecognized because caregivers' are treated as an undifferentiated group; results are blended under the generic category of `caregiver'. Conclusions are then drawn from the study that may contradict previous studies where the group `caregiver' has been differently composed. Increased attention to the variations in types of caring relationships is required (Wenger, 1987).

Operationally then, the term `caregiver', has been inconsistently defined and applied. This results in considerable confusion interpreting the contribution of the stress/burden research for understanding the needs of the spouse caring for a cognitively impaired partner. But more than just a methodological problem, this generic use of `caregiver' exemplifies a more fundamental problem with the concept. Again, what specifically is a `caregiver'? A

number of criticisms regarding the use and understanding of this concept prevail throughout the literature.

First, considerable attention has been devoted to examining the dual nature of caring as both an affective expression and an activity (Baines et al., 1992, 1991; Abel, 1990; Aronson, 1991; Graham, 1983; Groves and Finch, 1983). However, within the caregiving literature, there has been a tendency to strip caregiving of its emotional context and to redefine it as `tending' (Abel, 1990). For example, Braithwaite (1990) defines a caregiver in the following way:

> (a person) who assume(s) the major responsibility for providing or organizing services on a regular basis to someone who is incapable of providing for her or himself (Braithwaite, 1990 p.36)

Similarly Morris (1994) notes that `informal carer' is a socially constructed term used to identify those who have a personal relationship with a disabled person and who provide them with some form of help: This definition is much more heavily associated with the `taking charge of' definition than it is with the `caring about' definition.

Abel (1990) suggests that although the focus on tasks has some merit, it also limits understanding of the endeavour of caregivers' - "chores are embedded in intimate personal relationships and concentration on tasks may blind us to what is most distinctive about this activity" (Abel, 1990 p.139). Graham (1983) echoes this concern and suggests that caregiving can not be understood objectively and abstractly but only as a subjective experience. Unfortunately, the vast majority of the literature on caregivers' has employed

quantitative methods that reduce the caregiving experience by ignoring the affective component of the caregiving role on task fulfilment.

Even worse, some researchers have acknowledged the dual nature of caring but have made the assumption that caregiving is the behavioural expression of the affective component of caring - `affirmation of one's commitment to the welfare of another' notes one group of researchers (Pearlin et al., 1990). This mind-set can be dangerous and limiting. For example, in their analysis of women and caring, Baines et al., (1991) suggest that:

> while the notion of caring incorporates both labour and love, the assumption that they are inseparable can call into question the integrity of a woman's caring about when she is no longer able to care for (Baines et al., 1991 p.15)

This notion that providing care is necessarily indicative of emotional caring reinforces the pejorative connotations of institutionalization and may also discourage the use of supportive services - relinquishing aspects of providing care may be perceived as demonstrating a lack of caring. For example, Harper and Lund (1990) found it necessary to rationalize their inclusion of relatives of institutionalized patients as 'caregivers' because they recognized that this description might seem "incongruous" (p.264).

In other words, within the current literature, the `caring' element of caregiving has been either ignored or assumed. The repercussions of this oversight include a seriously restricted understanding of the caregiver and his/her experiences and a subtle, but powerful pressure on family to provide concrete care in order to demonstrate their love.

A second problem related to the concept of `caregiver' regards the generalizations

that this concept evokes. In particular, consistent throughout the caregiving literature is the presumption that caregivers' are, ipso facto, good and `morally worthy' people (Askham, 1991; Aronson, 1986). Fiske, Coyne and Smity (1991) comment upon the `almost Pollyannaish image' of the contribution of social relationships to adaption in the social support literature. For example, one article summarizing the findings in the caregiving literature begins by identifying caregivers' as `highly responsible agents who provide substantial physical, emotional, social and economic support to their chronically ill elder relatives' (Gallagher, 1985, p.259).

This assumption helps to segregate caregivers' as a distinctive group with an entity that supersedes individual identity. This results in a tendency for this perspective to strip the person fulfilling the caregiving function of their individual identity; caregivers' are viewed primarily from the position of someone who provides care to the `patient'. This failure to `see' the individual providing care to an impaired older person severely limits understanding of his/her needs.

In summary, although there is a massive body of research on family caregivers', there remain glaring gaps in understanding. In particular, there is only limited understanding of how the family caregiver perceives his/her situation and subsequently identifies his/her needs because few studies have been grounded in the experience of the caregivers' themselves (Willoughby and Keating, 1991). Since research demonstrates clearly that the unrelieved stress of the caregiving role can have a detrimental effect on the health and well-being of the caregiver particularly if he or she is a spouse, this is an important oversight. To begin to conceptualize their `needs' then, it is important to have a clearer understanding of how the

experience of caring for an impaired partner is perceived.

PURPOSE OF THE RESEARCH STUDY

Recognizing the gaps in our understanding, the purpose of this study was to improve understanding of service utilization issues for spouses living with a partner who is suffering from dementia. Specifically, I wanted to develop insight into what the experience looked like and explore how this experience interfaced with the use of formal support services.

Arising from the literature, some of the questions that I had in beginning this project include the following:

1. How is a `perceived need' for formal support service developed?

2. How does gender impact perception, and/or utilization, of home-support services.

3. How is the `beneficiary' of services defined (ie. whose needs are support services identified as meeting)?

4. How does the well partner label him/herself? Does this labeling of self impact perception of formal support?

CHAPTER 2

METHODOLOGY

INTRODUCTION

In this chapter I present the methodology that I used to develop an understanding of how the experience of living with a memory impaired partner interfaced with the use of services. First, I will provide an overview of the rationale for utilizing a qualitative research method. Next, I will highlight the theoretical principles that grounded my understanding of the research process. I will then outline the steps taken in the research process including a discussion of my analytic process.

RATIONALE

This study employed a qualitative research method. The rationale for selecting this method of inquiry as the most suitable for exploring this problem area included the following:

1. As previously noted, the majority of both caregiver and service utilization research has, to date, been quantitative. A number of questions have been raised by this research but the structured format of the methodology has precluded a more in–depth, comprehensive exploration. Unlike a quantitative research design, the qualitative design allows the flexibility to respond to the data as it emerges; ideas and insights can be pursued as they surface. As a result, it was anticipated that this method would yield a richer, more detailed understanding of service utilization

issues.

2. The vast majority of caregiver research has assumed a stress/burden paradigm for understanding and has been based on more conventional hypothesis testing formats. In other words, the focus of inquiry has been predirected by the theoretical premises being employed for understanding. This has provided a restrictive lens for understanding the experience of the spouse whose partner is suffering from dementia. In particular, this model promotes a pejorative understanding of caregivers who have been identified objectively as in distress and yet are unwilling to utilize `support services'; they are seen as `resistant'. This is disturbing because it problematizes the individual caregiver and precludes a more structural or situational analysis. In contrast, naturalistic inquiry attempts to ground understanding in the experiences of the participants; patterns, themes and categories of analysis emerge out of the data rather than being imposed on them prior to data collection and analysis (Patton, 1990). This encourages understanding to progress beyond the limited perspective currently espoused by the stress/burden paradigm by promoting a more open, holistic exploration of the issues. Broader understanding will assist service providers to better meet the needs of this group.

3. When this study was initiated, there was essentially no literature that explored the meaning associated with help seeking from the perspective of spousal caregivers' who are reluctant to utilize services. A qualitative method was the most appropriate

method for beginning this inquiry.

4. The importance of context in promoting increased understanding of this problem was assumed. Qualitative methods are better suited to exploring and understanding contextual issues than quantitative methods.

For these four reasons then, a qualitative research method was selected.

There are multiple perspectives associated with qualitative research methods. Three schools of thought can be identified that most clearly informed this project: hermeneutics, feminism and social constructionism. In the following section I will identify the relevant points of each of these perspectives as they relate to my methodology; I want to emphasize that it is not my intent to provide an exhaustive overview of these perspectives but rather to elucidate those aspects of each perspective that informed my understanding of the research process. Furthermore, I will not draw attention to the shared understandings of these perspectives, although I recognize that there are many overlaps. Instead, I will trace my understanding of the research process by focusing on how each influenced my particular process. My purpose in this section is to both identify the labels that I think can best be used to situate my project and to highlight the principles that I incorporated into my research process.

CONCEPTUAL FRAMEWORK

Hermeneutics

Hermeneutics is a branch of phenomenology which seeks to illuminate social, cultural, historical, economic, linguistic and other background aspects that frame and make comprehensible human practices and events (Addison, 1992). It is grounded in the everyday practices of individuals' lived experiences and seeks to interpret, or make meaning of, something that is not yet understood. The intent is to go beyond mere description of what is manifest in order to uncover hidden meanings as we live them in everyday life (Cohen and Omery, 1994; Van Manen, 1990). Hermeneutic phenomenology claims to be scientific because of its systematic, explicit, self-critical and intersubjective study of lived experience (Van Manen, 1990, p.11).

In contrast to more positivist research, hermeneutical research does not aim to control or explain, but rather offers the possibility of increased insights into everyday activities and meanings. It is the systematic attempt to uncover and describe the internal meaning structures of lived experience and should enlighten practice. The goal is identified as helping human beings to become increasingly thoughtful and better prepared to act tactfully in situations (Van Manen, 1990, p.21).

There is no specific research method associated with hermeneutic research (Van Manen, 1990; Addison, 1990). Addison (1992) however identifies several assumptions that guide a grounded hermeneutic approach. First, participants of research are meaning giving beings. Second, meaning is not spoken but is also expressed in action and practice.

For this reason, it is important to look at everyday practices and not just beliefs about those practices. Third, the meaning giving process occurs within a context; it is not entirely a free process. Fourth, meanings are rarely fixed, clear and unambiguous but rather are constantly being negotiated and change with time. Finally, there is no objective `truth'; interpretation is always necessary to understand human actions (Addison, 1992).

Several practices that are central to grounded hermeneutic research can be identified. Addison (1992) lists the following:

1. Immersing oneself in the participants' world in order to understand and interpret the participants' everyday practices.

2. Looking beyond individual actions, events and behaviours to a larger background context.

3. Entering into an active dialogue with the research participant, research colleagues, research critics, the account itself, and one's own values, assumptions, interpretations and understandings.

4. Maintaining a constantly questioning attitude in looking for misunderstandings, incomplete understanding, deeper understandings and alternate explanations.

5. Analyzing in a circular progression between parts and whole, foreground and

background, understanding and interpretation, and researcher and narrative account.

6. Offering a narrative account of the participant's everyday practices that opens new possibilities for self-reflection and changed practices.

7. Addressing the practical concerns of the researcher and the research participants against a larger social cultural, historical, political and economic background

These principles guided my research process.

As a philosophical foundation, hermeneutics informed my research process in two important ways. First, hermeneutics sensitized me to the importance of circular process of questioning, thinking and seeking understanding. "The hermeneutic task becomes of itself a questioning of things" (Gadamer, 1991/1975 p.269). This process requires that the researcher move back and forth between collecting, analyzing, reflecting, and writing. By going back and forth between the parts and the totality, a deepened understanding is achieved (Kvale, 1996; Addison, 1990; Van Manen, 1990). Steele (1989) describes the process as reading with a radical eye. This means that one should not only immerse oneself in a text and faithfully follow the author's intended argument, but that one is also capable of moving outside the text and viewing it from several different perspectives with an eye to seeing it more completely (Steele, 1989 p.224). This understanding grounded my research

process.

Specifically, for me, the research process can be defined as an ongoing dialogue - with the participants during the actual interview and then later with their transcripts; with the literature in the area; with other colleagues and members of my research committee; and, significantly, with myself. It meant questioning and requestioning both intellectual and emotional responses and understanding. Gadamer (1991/1975) calls this a dialectic because it is the art of conducting a real dialogue (p.367). This constant questioning stance embodied my understanding of the research process.

The second important way that hermeneutics informed my work regards its recognition of intersubjective knowing. Specifically, hermeneutics breaks down the false dichotomy between self knowledge and object; we can only understand something by recognizing ourselves in it (Gadamer, 1991/1975). This perspective recognizes that

> ...hermeneutically trained consciousness must be from the start, sensitive to the text's alterity. But this kind of sensitivity involves neither `neutrality' with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings. (Gadamer, 1991/1975 p.269)

In other words, the researcher's own history for understanding and interpretation is recognized as critical. Gadamer for example argues that tradition and prejudice, or pre-understanding, provide the basis for interpretation and therefore there are many experiences

of `truths' (Hekman, 1990). For me, this promoted personal ownership of my interpretation; rather than claiming to be (re)presenting the voices of the participants, the story being told in this thesis is mine.

Hermeneutics then, introduces recognition of the interpretive nature of `reality', the importance of the relationship between interviewer and interviewee, and the importance of the questioning cycle. However, there is an assumption that through the process of constantly questioning and revising one's understanding through a dialogue with the text one can reach a "sensible meaning, a valid unitary meaning, free of inner contradictions" (Kvale, 1996 p.47). Social constructionism takes this perspective a step further and introduces questions regarding the possibilities of a consensual, unified interpretation. As my research process progressed this perspective became increasingly important.

Social Constructionism

Social constructionism encompasses a range of approaches in psychology which share the view that our knowledge about ourselves is culturally bounded and that different cultural and subcultural systems entail different psychologies (Parker and Burman, 1993) Although there is no single description which would fit all social constructionists (Michael, 1996; Burr, 1995) , Burr (1995) identifies four key assumptions.

1. Social constructionism takes a critical stance towards taken-for-granted knowledge. It promotes a suspicious examination of our assumptions about how the world appears to be. In particular, it raises questions regarding the premises upon which divisive categories such as gender have been

established (p.3).

2. Consistent with hermeneutics, social constructionism assumes historical and cultural relativity. This means that specific ways of understanding are seen as products of a specific culture and history and are dependant upon the particular social and economic arrangements prevailing in that culture at that time; forms of knowledge are seen as artifacts as opposed to the `truth' (p.4).

3. Social constructionist theorists believe that knowledge is constructed and sustained by social processes. This means that it is through the daily interactions between people in the course of social life that our shared versions of knowledge are created (p.4).

4. Knowledge and action go together. This means that descriptions or constructions of the world sustain some patterns of social action and exclude others (p.5).

The cultural and intellectual `backcloth' against which social constructionism has taken shape is postmodernism (Burr, 1995 p.12). Postmodernism, alternately referenced by some as poststructuralism (Burman and Parker, 1993), is used here to describe an intellectual movement that rejects the idea that the world can be understood in terms of `grand theories' or `metanarratives'. It shifts the focus from a notion of preexisting stable

reality and instead recognizes the importance of language for constructing reality.

> For poststructuralist theory the common factor in the analysis of social organization, social meanings, power and individual consciousness is *language*. Language is the place where actual and possible forms of social organization and their likely social and political consequences are defined and contested. Yet it is also the place where our sense of ourselves, our subjectivity, is *constructed*. The assumption that subjectivity is constructed implies that it is not innate, not genetically determined, but socially produced (Weedon, 1987 p.21 - emphasis original)

Language then, far from reflecting an already given social reality, constructs this social reality for us. In other words, neither social reality nor the `natural' world has fixed intrinsic meanings that language expresses; rather, language is a "pre-condition for thought" (Burr, 1995) where meaning is produced within language as opposed to being reflected by it (Weedon, 1987). This shifts attention away from both a notion of an objective reality as well as the independent subject and focuses instead on language (Kvale, 1996).

Fundamental to a social constructionist view is the possibility of alternate constructions of the self and other `events' in one's world through language (Burr, 1995 p.34). In contrast to the humanist view, which characterizes most traditional psychological approaches, postmodernism, including social constructionism, challenges the notion of a fixed, coherent and rational subject who is capable of full consciousness and agency. Rather such a subject is `de-centred' (Lather, 1993; Michael, 1996) and "refashioned as a site of disarray and conflict inscribed by multiple contestatory discourses" (Lather, 1993 p.5).

This subject is seen as both producing and produced by prevailing discourses.

Similarly, the notion of an objective reality is challenged. Rather, grand narratives are replaced with "the contingent, messy, boundless, infinitely particular and endlessly still to be explained" (Murdoch quoted in Lather, 1993 p. 6) Objective reality is seen as simply the external reality to which our language and perceptions refer (John, 1994).

Rejecting the claims of `truth' however, is not to insinuate that there is no knowledge. Rather, poststructuralism claims that power enables some to define what is or is not considered knowledge. In other words, language is not a neutral reflection of experience because our linguistic categories are not neutral (Riger, 1992). Rather, discourses, which are seen as a structuring principle of society, represent political interests and are constantly vying for status and power (Weedon, 1987 p.41).

> At the level of the individual, poststructural theory is able to offer an explanation of where our experiences come from, why it is contradictory or incoherent and why and how it can change. It offers a way of understanding the importance of subjective motivations and the illusion of full subjectivity necessary for individuals to act in the world. It can also account for the political limitations of change at the level of subjective consciousness stressing the importance of the material relations and practices which constitute individuals as embodied subjects with particular but not inevitable forms of conscious and unconscious motivation and desires which are themselves the effect of the social institutions and processes which structure society. (Weedon, 1987 p.41)

My interpretation of postmodernism grounded this research process in several important ways. First, it promoted a "critical interrogation of the exclusionary operations by which `positions' are established. (Butler and Scott, 1992 xiv). As identified by Lather (1993) the essence of the postmodern argument is that the dualisms which continue to dominate Western thought are inadequate for understanding a world of multiple causes and effects interacting in complex and non-linear ways, all of which are rooted in a limitless array of historical and cultural specificities. Post-structuralism opens to question how these categories get constructed. For example, questions were raised regarding the construction of the category `resistant' in addition to issues around producing a gendered analysis without reproducing gender as a `natural' category.

Second, it introduces the expectation of contradictions, multiplicity, contingency and incomplete understandings and explanations. This required revising my expectations that by listening closely I would hear a coherent, rational story to tuning into the contradictions and inconsistencies in each participant's account. Moreover, particularly as I attempted to make sense of what the participants were saying, I was in conflict between my wish to neatly package my understanding and my sense of discomfort that irrespective of what could be said so much went unsaid. My analytic process then required that I try to make sense of these contradictions and differences in a way that they could be present in my story. It also required me to acknowledge that despite this effort, much remains unsaid.

Third, social constructionism directs attention to the use of language and the ways in which people tell their story. Specifically, there is growing recognition that narrative provides a very powerful means for understanding human experience (Somers and Gibson,

1994; Tappan and Brown, 1989) This new notion of narrative moves beyond the understanding of story as `representational', that is an accurate representation of reality which does not necessarily explain, to a new notion of narrative.

> [This new notion] recognizes narrative and narrativity to be concepts of social epistemology and social ontology. These concepts posit that it is through narrativity that we come to know, understand, and make sense of the social world, and it is through narratives and narrativity that we constitute our social identities. They [narrative theorist] argue therefore...[that] all of us come to be who we are (however ephemeral, multiple and changing) by locating ourselves (usually unconsciously) in social narratives *rarely of our own making*. (Somers and Gibson, 1994 p.59 - emphasis original)

On a practical level, this turned my attention to the importance of the stories that individuals had to tell about their experience living with a memory impaired partner. Rosenthal (1993) suggests that:

> The narrated life story represents the biographers overall construction of his or her past and anticipated life, in which biographically relevant experiences are linked up in a temporally and thematically consistent pattern" (Fisher, 1982) ...we can assume that the process of selection being carried out by the biographer while presenting his or her life story is not haphazard or arbitrary.... rather it is a process taking place simultaneously against the backdrop of a biographical structure of meaning which determines the selection of the individual episodes presented and within the context

of the interaction with a listener or imaginary audience. (Rosenthal 1993 p.63)

Taken a step further, culture is seen as `speaking itself' through an individual's story (Reissman, 1993; Rosenwald and Ochberg, 1992). `Deconstructing' the individual story then provides a means for beginning to uncover ideologies and discourses. This means that a goal of social constructionism becomes "disrupting and displacing dominant (oppressive) knowledges" in part by articulating the values supported by alternative conceptions of reality (Gavey, 1989 p. 462 quoted in Riger, 1992).

In summary then, a simplistic recognition of the influence of social constructionism in this research process is twofold. First, by challenging ideas that the individual is a coherent fixed entity, the possibilities of contradiction, change, and relationality are introduced. Second, the focus on language directed my attention to the importance of the stories that the participants told about their experiences as broader reflections of cultural reality.

Feminism

To this point I have tried to tease out some principles that guided my research process. These include: the importance of recognizing my own subjectivity within the research process; a focus on subjective, or cultural reality of the participants, as opposed to a search for one truth; the belief in the importance of `hearing' the participant's words; and recognition of language as both creating and reflecting reality. Underlying and complimenting these values, are the principles associated with feminist research. These

principles guided the actual design of the research and provided the analytic lens through which to interpret the participant's words. They also provided a grounding from which to combat the critique of social constructionism as promoting relativism.

The goal of feminist research is to challenge inequality and empower women and other marginalized groups (Cancian, 1992). In feminist social constructionist research, the goal is to disrupt and displace dominant (oppressive) knowledged in part by articulating the values supported by alternate conceptions of reality (Riger, 1992). This stance contrasts the detached, neutral stance typically advocated in research. It assumes an analytic lens that attempts to make explicit sites of oppression.

A key component of my understanding of feminism is its insistence that personal experience is the lived version of political reality. This means that:

> individual experience does not occur in a vacuum; it is one person's encounter with the social and cultural context which acts to inform and transform the inner meaning of that experience. (Brown, 1994 p.50)

This leads to the popular slogan "the personal is political". This means that individual experience is consciously de-privatized and holds potentially universal meaning (Brown, 1994 p.9).

> ...human experience is understood within this theoretical framework as the interaction between internal, personal phenomenological experience and the external social environment. Internal experience gives meaning to external reality, which in turn shapes and informs the comprehension of internal experience which then plays

again upon external reality, in a constantly interactive process. (Brown, 1994 p.62)

This understanding helped clarify the social constructionist focus on uncovering hidden ideologies and discourses and reframed my focus on resistance to service use as an individual problem to a social issue. It also highlighted the importance of focusing on everyday experience as a source of knowledge.

A second understanding underlying feminist research is that women, and other marginalized groups, can be knowers and that their experience can be a source of knowledge (Wuest, 1995). This research project was developed under the assumption that spouses living with a memory impaired partner had something important to contribute to our understanding about 'caregivers' that was not being heard. Throughout the research process, I attempted to honor their expertise over their experience and to recognize what they had to say as important.

A third principle of feminist research that influenced this project was the intention to reduce inequities in power between myself, as researcher, and the participants (Wuest, 1995; Cancian, 1992; Gottlieb and Bombyk, 1987; Harding, 1987). This was done in several ways. First, participants were encouraged to take control of the interview by the absence of a structured format. Second, interviews were scheduled according to the expressed wishes of the participants related to time and location. Third, I responded to participants' personal questions about me honestly and openly rather than preserving a more traditionally sanctioned facade of impersonality and distance. Fourth, transcripts were returned to participants and feedback sought regarding the accuracy of both what I had heard,

and where possible, how I understood the material. Finally, I attempted to establish the power of the participants by recognizing both explicitly and implicitly their expertise, acknowledging that "they had something I did not and they chose whether or not to share it with me (Horn, 1995 p. 96).

To this point, I have outlined the conceptual practices which guided my understanding of the research process. Specifically, I have drawn on hermeneutics, social constructionism and feminism in an attempt to ground the decisions I have made in carrying out this research study. Now I will chronicle the actual research process.

THE RESEARCH PROCESS

This was a qualitative study using open-ended interviews. Fourteen participants were interviewed over a ten month period between September 1993 and June 1994. Most were interviewed at least twice. The interviews were taped and transcribed verbatim. The transcripts were then analyzed using both an adapted constant comparative method and discourse analysis.

Locating Participants

The original focus of this study was on spouses living in the community with a partner diagnosed with dementia and who had been referred for home support services but had been reluctant to accept these services. This latter criterion was based on the assumption that a referral for services indicated that someone had identified some need for

this type of service for this couple - ie. some `objective' need had been established. Also, my decision to limit the focus to spouses was deliberate; I recognized the uniqueness of their relationship and felt that their experience would be qualitatively different from that of other family members serving as informal caregivers.

To locate potential participants I approached a variety of community-based service providers. I explained the purpose of my project and requested that service providers contact any individuals whom they identified as potentially suitable to determine if they would be interested in finding out more about the study. When interest was expressed, potential participants were offered the choice of either contacting me directly or giving permission to the service provider to supply me with the potential participant's name and telephone number so that I could contact them directly.

Initial criteria for participation included the following:

a) S/he was living with a marital or common-law partner who was experiencing problems with deteriorating memory. A diagnosis was not required.

b) The relationship between the two partners predated the onset of symptoms

c) A referral had been initiated to a home support agency for either homemaking or respite care

d) The caregiving partner was identified as demonstrating some reluctance to actually accept these services.

e) S/he was willing to participate and spoke English.

As the study progressed however, consistent with an emerging qualitative design

(Lincoln and Guba, 1985) these criteria were modified in order to introduce `maximum variation' (Patton, 1990). In other words, participants were solicited who could offer as broad an understanding as possible. Specifically, based on the intent to extend the insight gathered from previous participants, later participants were actively sought who could provide contrasting insight. For example, this resulted in recruiting two women who had extensively used services.

In total fifteen individuals were referred to my study between October 1993 and June 1994. Except for one individual, all the referrals came from professionals with whom I had a previous working relationship.

My initial contact with potential participants was by telephone. During this telephone conversation I explained the purpose of my study and assured individuals that participation was completely voluntary and would not affect their involvement with the referring service provider. If interested and willing a personal interview was scheduled. Of the fifteen individuals who were referred to the study, all initially agreed to participate following this telephone contact. However, one woman was, and remained, unprepared to schedule an interview related to her caregiving responsibilities and eventually decided against participating.

As a result, fourteen individuals participated in this study. Three were interviewed only once, ten were interviewed twice and two participants were seen three times. Additional telephone contact was made with several participants to clarify information. The length of each interview varied, ranging from one hour to three and a half hours. Total time spent with each participant ranged from ninety minutes to almost eight hours and averaged

over four hours for those interviewed at least twice.

A brief overview of each participant[1] is provided below. First I will introduce the six women who participated, followed by the eight men.

Alice Cook is a 63 year old married woman whose husband was diagnosed with Alzheimer's Disease more than five years ago. Until recently, Mrs. Cook maintained her husband at home by personally attending to all of his care needs while simultaneously managing the care of her mother who also suffered from a dementia. When I met her, Mrs. Cook was being treated for depression, her husband had just been admitted to the local hospital related to her own physical and emotional deterioration, and her mother had died two months earlier. Mrs. Cook has one daughter living in a nearby city and with whom she maintains some contact but on whom she prefers not to rely. Similarly, although she had used the formal support system to assist with the care of her mother, Mrs. Cook had not been receptive to involving formal services in the care of her husband. At the time of the interviews, Mrs. Cook lived in the couple's marital home in a small residential subdivision and spent most of each day at the hospital with her husband.

Olga Knight is also in her early 60's and had been the sole caretaker for her husband until his very recent admission to a long term care facility. (She emphasized that it

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[1] All names are fictitious

was her husband's decision to move although she also acknowledged how difficult it had been looking after him). He was physically mobile but mentally he was easily disoriented and forgetful so required constant supervision. Except for a sister-in-law who lived in the same condominium, Mrs. Knight had no family involvement. The couple were childless and their extended families lived overseas. Mrs. Knight received periodic support from her friends and had regular contact with a psychiatrist who was treating her for depression. Since her husband's placement Mrs. Knight had become an active volunteer with the facility.

Louisa Ford, a 60 year old woman, has turned her executive home into `an institution' in order to care for her 90 year old husband who suffers from Parkinson's Disease and Alzheimer's. She had been married for less than a year when her husband, an affluent professional businessman, began to experience health problems about fifteen years ago. Mrs. Ford left her position as a teacher about ten years ago because her husband required 24 hour supervision. She is a strong advocate for the rights of caregivers and has relied extensively on formal support - both public and private - to assist her in the care of her husband. She sees herself as a primary caregiver with no family on whom she can rely. Her relationship with the closest kin, her husband's children from his first marriage, is strained and her extended family is nominally supportive but geographically unavailable. Mrs. Ford expressed grave concerns about her future given the financial devastation this experience has wrought.

Ann White lives in a small one bedroom apartment with her physically mobile but cognitively impaired husband. The couple met about twenty years ago. It is a second marriage for both and has historically been rocky. Mrs. White's current situation is characterized by her husband's physical and verbal aggression and belligerence and an upsetting, antagonistic relationship with his three children from his first marriage. She feels socially isolated and that her vigilant care to her husband is completely unrecognized. Recently, she has decided that her husband should be placed in a care facility because attending to his care needs is causing too much physical and emotional damage to her; she too is using psychotropic medication to help her cope and has been unable to accommodate the recommended follow-up to cancer surgery. However, she is ambivalent about proceeding both because she feels guilty but also because of the void in her life that would result.

Despite her obvious fatigue, Maria Deboni presented herself as a fighter dedicated to the care of her totally dependent husband. He had suffered for several years from a complicated dementing process and then three years ago he had a major stroke which left him physically incapacitated and virtually unable to communicate. Mrs. Deboni manages to meet his needs for total care in the family home that her husband built many years ago. She feels strongly supported by her only son and his wife but is reluctant to share caregiving activities with them because she does not see this as their responsibility. She did however have a private helper who attended her

husband daily while Mrs. Deboni was employed outside the home. Mrs. Deboni was vehement that her husband would never be placed in a facility and was angered by the inadequate support that was being offered to her.

Bea Macneil is a lively, `earthy' woman who lives with her 84 year old husband, Tom, in a large hi-rise apartment building. Mr. Macneil, a warm, pleasant and complacent man, looks to her to provide direction because his own memory is failing. The couple have no diagnosis to account for his deteriorating memory but attribute it to complications (caused they firmly believe by medical incompetence and insensitivity) following surgery and perhaps diabetes. In public, Mrs. Macneil presented a strong competent facade but later in private she acknowledged how disheartening and draining the situation is for her. The couple are close to their three children but, recognizing that they all have busy lives, see them only as back-up emergency support. In the past the Macneil's maintained a busy lifestyle but this has changed because Mr. Macneil is becoming increasingly uncomfortable socializing and Mrs. Macneil sees her role as beside her husband taking care of him.

Gordon Archer is a 67 year old retired educator who left his teaching job two years ago in order to manage the care of his wife, Penny. She has been diagnosed as having Alzheimer's Disease and although physically quite fit is mentally unable to consistently attend to her own needs. Mrs. Archer participates in a community day program twice a week which allows Mr. Archer time to attend to household

management tasks. Mr. Archer feels quite isolated and alone as primary caregiver. Although he has no complaints regarding his relationship with his two sons, and considers them as involved as one might expect, Mr. Archer feels he cannot rely upon them for assistance in the way that he could if they were daughters.

Dave Malloy, 74 years old, has been married to his wife Eunice for over fifty years. They met while he was serving overseas during WWII and have two children, a son and a daughter, who live within an hour's commute to Mr. Malloy. Mrs. Malloy began experiencing difficulties with her memory nearly ten years ago. Gradually the couple's active Senior's lifestyle ground to a halt as Mrs. Malloy became increasingly incapacitated and unwilling to participant. Mr. Malloy struggled for several years to attend to her needs. However, prior to our interview, recognizing how explosive the situation had become, he had his wife admitted to a care facility. His lifestyle is now divided between his daily visits to his wife and maintaining his home.

Harold Green is a physically fit 84 year old man who lives with his wife of 54 years in a large recently-built condominium apartment. Mr. Green owned his own landscaping business but is now retired. He thrives on being active and involved. Mrs. Green presents as a quiet woman who seems to keep herself busy in the background. Although I saw no noticeable signs of memory impairment during my very limited contact with her, Mr. Green indicates that she has been experiencing

increasing problems with her memory since his retirement about eight years ago. She has not been formally diagnosed but he believes she has Alzheimer's Disease. Mr. Green is disappointed by his two sons' limited involvement in their mother's care and feels that it is unfair that all the burden be placed on him. He has initiated involvement with several home support services but these contacts have not been overly successful; Mr. Green queries that they are responding to his needs.

John Lawson and his wife have been married for over fifty years and live in the same home in which they raised their three children; Mr. Lawson hopes to bequeath this home to his son when he dies so he is cautious about expenditures. His wife was diagnosed as suffering from Alzheimer's Disease about a year ago - a diagnosis that Mr. Lawson had suspected for several years prior to the actual confirmation. Throughout their marital relationship the couple had maintained a traditional lifestyle with Mr. Lawson working outside the home in an executive management position and Mrs. Lawson supporting him through her work in the home. Mr. Lawson retired about fourteen years ago but continued to remain quite active professionally on an ad hoc basis. He gave up this part-time work about three years ago because he could no longer leave his wife alone related to her deteriorating cognitive abilities and he could identify no other viable alternative arrangements for her care. He did not want to burden his children and the respite services provided through a local homesuppport agency were positively viewed but considered too expensive to be regularly relied upon; these services however were periodically used

and their availability introduced a measure of security for Mr. Lawson. Mr. Lawson presented as a very competent, self-assured man who felt he could continue to cope with his wife's care indefinitely as long as she remained co-operative. Although there was a period when she was becoming quite aggressive, medication is now helping to assure this. Mr. Lawson repeatedly identified he and his wife as private people who did not want to be bothered by others.

Ken Lowe and his wife continue to live together in the lovely home that they have shared for many years. Although described as his former `best friend' Mrs. Lowe has now deteriorated to the point that she is unable to maintain a conversation due to Alzheimer's Disease. Mr. Lowe mourns the loss of the woman he once knew. He feels lucky though because his wife is physically so healthy and continues to be amiable and co-operative . Mr. Lowe looks younger than his mid 70's age but indicates that since he began looking after his wife he has lost considerable weight, suffers from arthritis, and constantly feels fatigued and lacking in energy. A sense of hopelessness and despair generally permeated Mr. Lowe's conversation. Periodically this was interrupted when he began to speak disparagingly about the community response to his plight. Mr. Lowe received daily phone calls from his two sons and daughter but felt ultimately that he was alone in the responsibility of caring for his wife. He repeatedly identified the need for respite and did have his wife attending a community day program twice a week but otherwise felt that in-home services were futile and institutional care was inadequate.

Greg Jones, 79 years old, feels exhausted and unable to continue caring for his wife of over fifty years. She was diagnosed with Alzheimer's Disease several years ago and now relies upon Mr. Jones to be her "mind". Mr. Jones has decided that he cannot continue to maintain his wife at home at least partially because of her verbal aggression and unwillingness to co-operate. He is waiting for a vacancy in a nearby care facility. In the interim, he has initiated the involvement of a formal service provider so that he can have some time to look after his own needs. He has only words of praise regarding this service. Before resorting to formal supports Mr. Jones tried to involve his children - two sons and a daughter - in his wife's care but his daughter was unavailable to help and physical aggression resulted between his son and his wife when his son attempted to help, so these arrangements were seen as unworkable. I did not meet Mrs. Jones; at Mr.Jones request the interviews with him took place in my home.

Arnie Cashin was in his early 80's and his wife was nearly ninety years old when I met them. They lived together in the home that they had purchased nearly forty years earlier. Over the past few years Mr. Cashin had reluctantly taken on most of the home-upkeep tasks because his wife no longer seemed able to manage; she was however still looking after her own personal care needs. Mr. Cashin was somewhat bewildered by his wife's deterioration and could not understand the changes. In addition to increasing problems with her memory (that had not yet been diagnosed) Mrs. Cashin was quite hard of hearing and routinely misplaced her hearing aid, so

communicating with her was very difficult. Mr. Cashin a proud, independent man who took his responsibilities in life quite seriously, wanted to fulfill his "obligations" to his wife but was beginning to query that placement in a care facility might not be best for both of them. Having married late in life - Mrs. Cashin was in her early 40's before they felt financially secure enough to wed - the couple had not had children; recently Mr. Cashin has begun to regret this because it means that now he is on his own.

Mike and Ethel O'Malley resided in their own bungalow in a small rural city. Throughout their married life, Mr. O'Malley had maintained steady employment with the railroad and Mrs. O'Malley had maintained the home. She took great pride in her homemaking skills so was devastated when following a stroke, she was forced to depend upon others to have her care needs met; the stroke resulted in physical weakness and instability, and impaired speech and ability to communicate. Her husband, retired by this time, willingly picked up many of the home-making tasks and the couple's daughter visited daily to assist Mrs. O'Malley with her personal care needs. Although formal services had been offered, both Mr. and Mrs. O'Malley were insistent that they preferred to manage on their own. They presented themselves as very private, family-oriented people.

The Interview Process

Participants were given a choice regarding the location of the personal interview. Thirteen of the fourteen selected their own homes and one man chose to come to my house because he felt it would be too disruptive trying to talk in the presence of his wife.

There were disadvantages associated with having the interviews take place in the participants' home. Specifically, with nine of the participants their partner was also at home; several times this created some disruption to the interview process and it interfered with the possibility of having a private conversation. At least one woman was considerably more guarded in what she would say because her husband was present. On the other hand, this location was comfortable to the participants, facilitated their participation by requiring less effort and disruption to their daily routines, and provided an excellent opportunity to observe directly what their experience looked like; Reinherz (1992) recognizes this as a `valuable reflection of reality' (p.19) and Lincoln and Guba (1985) note the importance of context for giving meaning suggesting that `no phenomenon can be understood out of relationship to the time and context that spawned, harboured, and supported it' (p.189).

The initial interview was an unstructured interview and began with a request to "Tell me what it's been like for you since your husband/wife began having problems with his/her memory". This is an example of a `grand-tour' question (Spradley, 1979) which was intended to serve three purposes: first, I wanted to overcome the initial anxiety associated with the interview process by relaxing the participant and encouraging him/her to talk from a place in which he/she was `expert' (ie. of their experience); second, I wanted to insure from the beginning that issues pertinent to the participant were identified; finally, I wanted

to elicit stories as opposed to report (Chase, 1995) because this would provide better insight into the participant's subjective experience. The remainder of the interview involved trying to immerse myself into the participant's story by listening intently and seeking clarifications. Because I was interested in how personal experience interfaced with the use of services, if the participant did not spontaneously address the use of services, I introduced the topic and probed for information regarding their experiences with the formal service delivery system.

The value of this open-ended interview format is well supported in the literature. For example, Reinharz (1992) indicates that it `allows the research question, not the method, to drive the project forward' and it `encourages creativity' (p.23). This type of interview is described as "interviewee oriented" (Reinharz, 1992 p. 21 quoting Bart and O'Brien, 1984) with a firm focus of uncovering the participant's experience as opposed to imposing the researcher's own understanding of the issues (Reinharz, 1992 p.24). Similarly, Patton (1990) notes the following strengths of informal open interview: the salience and relevance of questions are increased; interviews are built on and emerge from observations; and the interview can be matched to individuals and circumstances (p. 288). Opie (1992) describes this mode of interviewing as "responsive" with a strong potential to empower participants both because they have some control regarding the interview process and content, and because this process affords them the opportunity to contribute significantly to the description and analysis of a social issue (p.64).

> ...unstructured and responsive interviewing, when used reflexively, can enable especially the socially marginalized to be empowered because it assumes they can contribute significantly to the description and analysis of

> a social issue...By taking part in the research they lift the veil of invisibility surrounding carers' everyday lives and the experience of marginality from their existence (by becoming centre, even if briefly) thus opening what is generally a socially obscured experience to a more public gaze (Opie, 1992 p.44)

Minister (1991) suggests this form of interviewing is particularly important for women and marginalized groups. She problematizes the assumptions inherent in a more structured interview by suggesting that a list of topics force the narrator to tell her story according to a chronology that reflects the interviewer's analytic thinking but not necessarily the narrator's. Also, a list tempts one to control interview topics. She concludes that "topic lists double-bind oral historians and deafens them to emergent meanings and to opportunities to draw out narrators' experience" (p.37).

Another identified advantage of an open-ended structure is that it facilitates an analysis that moves beyond content. Smith (1987) for example notes that an unstructured interview affords informants the freedom regarding how they tell a story that is essential to the analysis; the process is not disrupted by the procedures and therefore should yield stretches of talk that "express" the social organization and relations of the setting (p.189). Similarly, other discourse analysis (e.g.. Mishler, 1986; Rosenthal, 1993) promote the importance of uninterrupted speech.

In keeping with the open-ended focus, I made the decision not to actively seek basic demographic information. I was concerned that this sort of questioning would to some

extent force the participant's `story' into more conventional parameters. In contrast, my intent was to enable participants to ground their experience in the `facts' that they identified as important; in other words, they established their own context for their `story'. Retrospectively, this was a useful decision which provided valuable analytic information.

At the end of this first interview, I discussed with the participant what my next step would be and provided an approximate time frame for recontacting him/her. The willingness to be interviewed a second time was explored and plans were made for insuring that the participant received a copy of the interview transcript. Prior to leaving, I invited participants to contact me should they think of something that they felt I should know and I thanked them for sharing their experience with me.

Approximately three weeks after the first interview, a second interview was scheduled at a mutually convenient time. Although all had initially agreed to this second interview ultimately I was unable to re-interview three participants; one woman indicated she felt too stressed to continue participating, another woman canceled the second interview because she felt her time would be better spent volunteering in the care facility where her husband had been placed, and a third participant died shortly after the first interview.

This second interview focused on clarifying and expanding the understanding obtained during the first interview. It began with a review of the initial interview transcript. Interestingly, although most participants requested a copy of this transcript it prompted little discussion. Several had not read it by the second interview, and of those who had, most had primarily editorial comments to make. This was enlightening to me. It seemed that the value of providing the participants with a copy of the transcript did not lay in its use as a

means of promoting collaboration or fostering further conversation. Rather, several participants expressed pleasure in having a tangible chronicle of both their experience and their participation in the research; two participants for example verbalized their feeling that now their story had been written and would not die with them.

I exerted more control in the direction of this second interview than I had in the first. Participants were given the opportunity to add any information or insights that they felt had been left out after the first interview but I went into the interview with specific questions arising from my review of my notes and the transcript. In particular, I attempted to address any inconsistencies or gaps that were apparent. Additionally, especially with participants who were interviewed later in the research process, I used this second interview to check out ideas and hunches that had emerged during previous interviews with others. For example, because issues related to physical aggression surfaced so frequently during earlier interviews, I purposefully began to insure that this topic was explored during later interviews. Similarly issues associated with recognition and loss of control arose early in the interviewing process as seemingly important so were specifically addressed in later interviews.

This second interview was important in promoting deeper insight. It provided the opportunity to clarify information provided during the first interview and delve deeper into inconsistencies or gaps in understanding. For example, Reinherz (1992) notes that:

> multiple interviews are likely to be more accurate than single interviews because of the opportunity to ask additional questions and get corrective feedback on previously obtained information. As time passes, the researcher also can see how thoughts are

situated in particular circumstances (p.37)

Similarly, Lincoln and Guba (1985) indicate that `prolonged engagement' increases the credibility of data collection because it offers the opportunity to establish trust between the participant and the researcher and it allows the researcher to move beyond his/her own initial preconceptions. Van Manen (1990) suggests that multiple interviews are conducive to `collaborative hermeneutic conversations' because it encourages participants to reflect upon their experiences in order to determine deeper meanings (p.99). I found that most participants were more comfortable with me during the second interview.

With two of the participants a third interview was scheduled. One participant decided to involve formal support services following our first interview and I was interested in hearing his experience once the service actually started. With a second man, I felt my understanding remained so superficial and incomplete at the end of the second interview that I requested a third interview.

Following the last interview with each participant I sent a `thank-you' card which acknowledged my gratitude for their participation, recognized the usefulness of their contribution, and invited participants to contact me about the project in the future should they wish.

Data Management

Permission was requested from all participants to audio-tape the interviews. Although several were initially somewhat intimidated about being recorded, all agreed. For many, the tape recorder remained a presence throughout the interview. For example, one

woman whispered many of her negative comments about service providers because she did not want the tape recorder to hear. Other participants suggested at times during the interview that I turn the tape-recorder off temporarily because they were not saying anything important enough to require taping. In contrast, another woman checked to make sure that the recorder was working when she had a point she felt was particularly important. Another woman began to cry during the interview and requested that the recorder be shut off. One man made repeated references throughout the interview to the fact that historically he had generally refused requests to be taped.

Immediately after leaving the interview a field note was completed. In it, I summarized the emotional tone and overall impressions of the interview. This included drawing a general description of the participant and his/her environment, identifying any difficulties or idiosyncrasies with the interview process, and tentatively outlining major topical themes and issues. I paid particular attention to my own responses and reactions to the interview.

All the tapes were transcribed verbatim and included pauses, false starts, grammatical errors and repetitions. The first interview was transcribed by me and the remainder were professionally transcribed. I then listened to each tape while reading the transcript; This was both to check for accuracy and to insert non-vocal indicators such as changes in tone or speech rate. Simultaneously, I began documenting ideas and questions that arose while reading the transcript.

Data Analysis

Data analysis and interpretation proceeded in a circular, iterative fashion moving among the activities of information seeking, contemplation and writing. The goal was to develop deeper insight into the experience of living with a memory impaired partner through a reflexive process which gradually uncovered the layers associated with the experience. Williams (1990) describes the researcher's task in this process as "pull[ing] together the bits and pieces of the so called actor's construction of what is going on to create her own construction" (p.254). This description recognizes what for me was the critical component of the analytic and interpretive process: developing a representation of this data that reflected my own theoretical and political perspective while still maintaining the integrity of the data from the perspective of the participants (Opie, 1992). Lather (1991) too identifies the challenge of this process:

> The question becomes how to produce an analysis which goes beyond the experience of the researched while still granting them full subjectivity. How do we explain the lives of others without violating their reality? (Acker et al., 1983 quoted in Lather, 1991 p.74)

Brown (1994) describes this as a dynamic tension in feminist therapy, the contradictions between honoring each person's unique experience of reality while simultaneously attempting to make interpretations and interventions that place the private within the framework of the public and collective.

I wrestled with this dilemma throughout the analytic and interpretive process. As I outline the steps taken in analyzing the data I will address the ways in which I tried to insure

that I `heard' what the participants were trying to tell me. Their stories provided the foundation for my story. However, ultimately their stories were filtered through my own experience. The questions I asked of the data reflect my subjectivity. The understanding I reached therefore tries to account for the individual experiences of all fourteen participants while simultaneously realizing that my `truth' is not necessarily an accurate representation of each of the participant's individual truths.

Preliminary Analysis

Data analysis began after the first interview. The first stage in my analytic process can best be described as an increasingly detailed reading of the interview transcript focused on beginning to isolate the themes which structured the experience. Van Manen (1991) identifies three ways for doing this: a holistic approach which focuses on identifying sentences or phrases which capture the fundamental meaning of the text as a whole; a selective or highlighting approach which searches for statements or phrases that seem particularly essential or revealing about the experience being described; and a detailed or line-by-line approach which examines each sentence or sentence cluster to determine what it reveals about the experience. Initially, I employed the second approach. I read and reread the interview transcript in order to begin to highlight key phrases. These were phrases or sentences that stood out in some way as having great meaning to the person - for example they could be comments that had strong emotional content or tone, sentences which included linguistic intensifiers (ie. `very, very hard') or discourse markers such as `so' and `because', and evaluative clauses (Luborsky, 1994). Some of these key phrases were given

names which I felt captured their conceptual meaning while others were simply tagged as important.

I then attempted to develop the meaning of these key phrases by examining each phrase individually, as part of the general text and in relation to other research or theory in the area. Consistent with the hermeneutic circle, I moved back and forth between parts of the text and the text as a whole (Kvale, 1996).

Through this process, I pulled out from each interview transcript what I saw as the key issues or themes running through the participant's story. During a second interview with the participant I presented my understanding of the primary issues and asked for feedback. Initially, the themes were case specific; each participant's story was read in isolation of the next. However, as the study progressed, I then began to compare main ideas and themes across the cases and to use the interviews and personal journaling to develop these ideas.

Detailed Analysis

As I began to feel that I had interviewed a sufficient number of participants to develop an understanding of the experience I settled into the second stage of the analytic process. While initially the conversation had primarily been between me and the participants, it was now increasingly between me and the interview transcripts. At this point, I began a much more detailed, systematic reading of each transcript.

In addition to highlighting key phrases I also started to capture the content of what was being said through a line-by-line reading of the transcript. During this procedure, I began to isolate various aspects emerging as part of the experience and give them names.

This was done by reflectively considering each segment of the transcript to determine what it was about and assigning pieces of information that seemed to be related to the same category. The initial categories that were developed were predominantly topical and segments of the transcript could be placed in more than one category. Examples of early categories included `service use', `relationship changes' and `disease process'. A second run through the data asking the question `what is the meaning of this?" (Van Manen, 1991) resulted in the development of several conceptual categories, or themes, such as `isolation', `invisibility' and `control issues'. Segments of the data were coded using these categories.

This information was then entered into the computer using the qualitative analysis package `Ethnograph'. This process allowed me to begin pulling the interview material apart in order to put it back together again in different ways. For example, I could isolate everything related to the concept of control, both within a case and across all of the cases, and then compare and contrast the segments in order to begin elaborating the essence of it as a category. While this process facilitated a detailed analysis of specific categories, it also had the disadvantage of decontextualizing statements and fracturing the participant's stories; accounts were removed from their narrative context and meaning was lost.

My next step was to begin to try to establish how the various categories that I had established fit together. Using index cards labeled with each of the identified categories, I physically began to map out various arrangements while simultaneously documenting the connections. Gradually a conceptual schema emerged and I began to formally write up my analysis.

Returning to the Individual

Something was wrong however. Although I felt I had identified important themes using the above process, I continued to feel frustrated with my understanding; it felt too contrived and simplistic. By this I mean that it failed to capture the complexities and contradictions which were present in each person's story. In order to deepen my understanding, I decided to return to specific cases to do a more intensive analysis.

The use of in depth case studies had two benefits. First, case studies have "the power to convey vividly the dimensions of an individual life in a way that can effectively demonstrate the relation between that person's life and societal arrangements (Reinherz, 1992 p.174). By exploring each individual's story as a whole I could develop and convey a richer understanding of the complexities and contradictions that each individual was facing. Second, developing the case studies provided an important step in the hermeneutic circle by allowing me to go back and forth between the individual experience and the general experience of the group of participants as a whole. The use of comparative case studies is advocated as particularly consistent with feminist research methods (Reissman, 1993; Swigonski, 1993; Reinherz, 1992).

Four cases were selected to develop as case studies. There is considerable controversy regarding what constitutes a `case' and how it should be selected (Stake, 1994; Ragin and Becker, 1992). For my purpose, I decided to focus on individual participants who were identified as having the potential to illuminate selected aspects of the experience of living with a memory impaired partner. These individual `cases' were selected for both their similarities and differences in order that I could examine each person's story independently

and in relation to the others.

I began by selecting the two participants whose personal stories about their experiences seemed to be the most divergent. Both were women. I developed in-depth case studies of these two women, constantly comparing their stories as I proceeded. From this analysis, the importance of locating the caring activities along a private/public continuum was discovered as an important theme for understanding service use. In order to consider gender as an organizing principle, I next chose to focus on the personal narratives of two husbands. Unlike the two women who had presented as so different, the men who participated in the study seemed more similar; differences were subtler and not immediately as obvious. As a result, it was more difficult deciding who of the men could provide the most insight. To help make a decision, I did a preliminary analysis of each husband's story exploring how they located their caring activities. The two men on whose stories I ultimately decided to focus were selected because they tended to differ in the degree that their caring activities were grounded in a public or private understanding. Both men were verbally fluent and had been interviewed early in the study so had been particularly instrumental in providing direction for subsequent interviews.

The interview transcripts for each individual `case' provided the data for constructing the case studies; my objective was to develop insight into each persons personal narrative. Given the disagreement about the precise understanding associated with the term `narrative' (Reissman, 1993) I note that I chose to use an inclusive understanding in which each set of transcripts was seen as the personal narrative, or story, of that individual's experience of living with a memory-impaired partner. Focusing on each person's narrative constituted a

shift in attention from the experience itself to how the individual talked about this experience. A narrative analysis opens for examination the forms of telling about the experience not simply the content of it - the question becomes why was this story told that way (Reissman, 1993). Maxwell (1996) describes this focus as a `contextualizing strategy'.

Two broad assumptions ground my understanding of the importance of these personal narratives. First, texts and stories are used to conceptualize the ways in which individuals develop systems of meaning and beliefs. People not only interpret but actually organize their experiences through storying and performing those stories (Laird, 1994; Bruner, 1987). Second, a personal story is organized according to culturally available, but tacit `reasoning procedures' (Widdicombe, 1993); as noted previously, culture `speaks itself' through an individual's story (Reissman, 1993; Rosenwald and Ochberg, 1992). This means that the personal story reflects the beliefs, ideas and messages to which one has been exposed as one has interacted with one's familiar, social, political, economic, spiritual, and cultural milieus (Grimm, Macy and Morales-Long, 1996). The analysis of the texts of personal narratives then not only makes visible the individual's experience but also helps to contextualize that experience within a broader socio-cultural context. From a political perspective this analysis can be used to comment on social processes that participate in the maintenance of structures of oppression (Kvale, 1996; Ristock and Pennell, 1996).

Analyzing these personal stories requires attending to both the content and how the story unfolds. The objective is to go beyond what is said directly to work out structures and relations of meaning that are not immediately apparent in a text (Kvale, 1996). This requires a sensitivity to the subtle nuances of voice, language and perspective (Brown and

Tappan, 1989 p.196). How this is done however is open for debate; there is no single, clearly defined method for analyzing personal texts (Coffey and Atkinson, 1996; Nye, 1994; Reissman, 1993; Burman and Parker, 1993).

> It is difficult to speak of `discourse' or even `discourse analysis' as a single unitary entity. Insofar as there could be said to be commonality, these approaches are united by a common attention to the significance and structuring effects of language and are associated with interpretive and reflexive styles of analysis.(Burman and Parker, 1993 p.3)

My own interpretive process incorporated the ideas of a number of discourse analysts (e.g.. Champon, 1994; Burman and Parker, 1993; Widdicombe, 1993; Mishler, 1992;1986) into a framework for examining the structure of the text proposed by Rosenthal (1993). Her particular focus is on discovering the mechanisms of selection guiding the narrator's choice of stories in relation to the general thematic orientation of the interview. The aim of analysis is to reconstruct the interactional significance of the narrator's actions, the underlying structure of one's interpretation of one's life, which may go beyond the narrator's own intentions. This requires reconstructing both the `life history', that is the chronological sequence of the experience, and the `life story', or the narrated story which provides the present meaning to the experience (Rosenthal, 1993 p.61).

Based on Rosenthal's guidelines, the first step in this process was to reconstruct to the degree possible, the actual sequence of events surrounding the experience. The focus was on extracting the `objective' data which can stand more or less independently of the narrator's own interpretation (Rosenthal, 1993). The intent was to begin to develop a picture

of what happened because this understanding is required as a reference for the `story'.

The next step was to examine how the personal story unfolded. Two assumptions grounded this process. First, the way in which one tells one story is not haphazard; rather there is an underlying rationale which accounts for how the story progresses. Second, every action represents a choice between the alternatives potentially available in a certain situation (Rosenthal, 1993 p. 66) The task of interpretation is to try to imagine which options are open to the person in relation to the choices actually made. This assists in uncovering those choices which are systematically excluded. The goal is to discover the underlying rules, or tacit reasoning procedures, that are being used to interpret the experience (Rosenthal, 1993; Widdicombe, 1993; Bruner, 1987).

The process through which the participant's story unfolded was systematically examined. The possible significance of each sequence was considered and tentative `hypothesis' were generated to account for the possible meanings contained in the particular sequence. As many possible explanations as possible were identified and recorded. The transcript was then used to support or dispute my understanding of what the particular sequence or phrase meant. To assist with this process I dialogued with the data. Questions I asked while reading included:

1. How does this story begin? What sense can I make of this beginning?
2. How does the story proceed? Why am I being given this information at this point. How does this follow the previous statement?
3. How is this connected to what has already been said? How can I account for the contradictions?

4. What is spontaneously volunteered and what comes up because of specific questions?

5. What is not being said?

In addition to scrutinizing the actual sequencing, I also attended closely to the use of language. My purpose was to attempt to see beyond the words; this is sometimes referenced as `deconstructing the text' where the objective is to grasp the `unwritten' by `teasing out' the normative assumptions embedded in the text (John, 1994). For example, I carefully examined the context of `but' and `because' statements as clues to how the participant was evaluating his or her actions. Similarly, words such as `naturally' or `of course' raised a red flag; what was being assumed in such a matter-of-fact manner? Syntax was considered. For example patterns around the use of verb tense and personal pronouns were identified as providing important insight into how the individual was making sense of the experience; shifts that occurred within a sentence were identified as especially critical because they signaled a change in content or viewpoint that required attention (Chambon, 1994).

Finally, how the individual had generated his or her story was considered. I re-listened to the tape while re-reading the transcript in order to attend to changes in pitch or tone. I noted when statements seemed to proceed in either a particularly faltering or fluid manner. I used this information to help contextualize the words that were being spoken.

In summary three processes were used to help read beyond the words of the individual stories. These included: examining the sequencing of how the story unfolded;

scrutinizing the use of language; and attending to the non-verbal intonations associated with the actual words.

Based on the ideas generated by this systematic reading, I began to construct case studies on the four selected individuals. These are presented in chapter 3 through 6. My intent is to convey the complexities and humanity of their experience through my reconstruction of their stories. I am also trying to set the stage for contextualizing the experience of living with a memory impaired partner within a broader societal contexts.

Throughout the process of developing in-depth understanding of each of these four individual's I constantly compared and contrasted their personal narratives in order to develop a broader understanding of the issues. For example, I compared plot lines or main themes of each person's story, examined critical turning points in each person's story, and paid particular attention to individual ways of using language. I continuously tried to generate ideas regarding the meanings of differences and then checked through the transcripts again to see if I could confirm or disconfirm my suppositions. By the time I finished writing the four case studies, a preliminary conceptual framework was emerging. In order to refine these ideas, I returned to the transcripts of the other participants, and the analytic notes and ideas that I had developed earlier, and began to explore their fit with my idea. This included re-examining the themes that had been developed in the previous stage of analysis and contextualizing them within this framework. Chapter 7 presents the conceptual framework that emerged from this process.

CHAPTER 3

CARING: `IT'S WHAT A WIFE DOES'

THE STORY OF ALICE COOK

Setting the Stage

Alice Cook is a 61 year old married woman whose husband was diagnosed as suffering from Alzheimer's Disease five years ago. An accountant by profession, Mr. Cook has now deteriorated to the point where he is unable to do even the most simple of tasks for himself. As a result of his deterioration, Mrs. Cook gradually assumed responsibility for overseeing all home upkeep tasks, organizing her husband's time, and looking after his self care needs. For several years, she received no assistance with his care. Four weeks prior to our first contact, Mrs. Cook's husband was hospitalized because she "wore out". When seen, he was in the hospital where he had deteriorated considerably and was not expected to return home.

Mrs. Cook was referred to my study by a Social Worker on a Community Mental Health team. The Social Worker saw Mrs. Cook as ideal for this study, but also felt that talking about her experience might be therapeutic for Mrs. Cook. Mrs. Cook was willing to participate. However, she voiced scepticism that she had anything to contribute and was only receptive to meeting with me providing the interview did not interfere with her husband's schedule; she indicated that she could be available for a maximum of 90 minutes between her husband's lunch and supper feedings, and would not commit to a second

interview unless her husband remained hospitalized in order to avoid the possibility of embarrassing him or depriving him of her undivided attention. This was my first clue of the extent that Alice Cook's life revolved around her husband's.

Two 90 minute interviews took place in Mrs. Cook home during her brief respite between her husband's lunch and dinner. She lives in an older bungalow in a small suburban community in Southern Ontario. Furnishings and decorating dated to the 1950's and the house presented as clean and organized albeit somewhat barren. Similarly, the outside of the home also looked maintained but not elaborate. Mrs. Cook displayed no pride in her home. Rather, she seemed to feel worn out by the attempt to maintain it, suggesting that there was no point since there was no-one available to appreciate the effort; she indicated that during the nearly eight week time lapse between my two visits, no other person had been in her home.

On both occasions when seen, Mrs. Cook looked emaciated, pale and drained. She gave the impression of someone who assumed a `no muss, no fuss', practical attitude toward her appearance; she was dressed in clean, polyester pants, a blouse and a matching button-up sweater, she wore no make-up, and her short brown hair was clean and neat. At one point during the interview she jokingly referenced her inattention to style. Given this seeming lack of interest in her appearance, it came as a surprise when I discovered that Mrs. Cook had been restricting herself to a vegetables-only diet for several years related to concerns about gaining weight; she had maintained this severely limited diet even as she prepared nutritionally balanced meals for her husband each day because he had been concerned about her getting fat.

Mrs. Cook presented as a very self-contained woman. I was impressed by her openness and honesty in her attempt to respond to my questions but sensed a stoic reserve. She described herself as someone who has "never been use to going to other people for help" and added that"I guess I always did everything that I could myself" . At one point during the interview, while talking about her strong feelings of guilt regarding her husband's hospitalization (and subsequent deterioration), Mrs. Cook began to sob quietly and requested that the tape-recorder be turned off. She apologized profusely for her tears. At another juncture she attempted to brush off her emotional reaction to the situation by laughingly describing herself as a "nutcase". I found myself frequently torn in my desire to offer comfort while simultaneously recognizing her struggle to retain her sense of self-sufficiency.

From the beginning of the interview, Mrs. Cook seemed to be seeking direction in what she `should' be saying; she began by asking how she should start and then frequently fell into silence waiting for active prompting from me. She volunteered almost no background information about herself which contributed to a difficulty in seeing her outside of her caregiving role. She appeared quite conscientious in her attempt to present a thoughtful, authentic account of her experience even though she continued to assert throughout both interviews that she couldn't see how her story could be helpful to me. I thought this view was related, at least partially, to Mrs. Cook's perception of herself as one, isolated individual; she claimed no sense of sameness with other caregivers' in similar situations because she saw their experience as "completely different".

Service Use

Mrs. Cook initially came to the attention of a community Social Worker when she sought advice regarding her mother who, like her husband, also suffered from a dementia. At that time, Mrs. Cook's mother was living in her own home in the same neighbourhood as Mrs. Cook. However, related to her memory problems, she was having increasing difficulty managing independently so was turning to Mrs. Cook, her only child, for assistance. Mrs. Cook was exhausted attempting to oversee both households, was felt uncertain how to handle some of her mother's particularly distressing behaviour, and felt guilty that she was short-changing both her husband and her mother. She claims she was helped by the Social Worker who gave her information which increased her understanding regarding her mother's condition. Later, with some encouragement from the Social Worker she agreed to arrange for in-home support for her mother "when it was becoming too stressful trying to go down there all the time". When the situation could no longer be managed even with these home support services, Mrs. Cook felt forced to `put' her mother in a home. She continued to visit her mother three times per week until her death two months prior to our interview.

Although she found the services helpful with her mother, Mrs. Cook adamantly refused to use home support services in her own home. For several years, she insisted upon coping on her own. Only when she became so exhausted and depressed that the family physician was considering *her* hospitalization, did she finally agree to try available home support services. However, services were only in place for three days before the situation broke down completely and Mrs. Cook had her husband admitted to the hospital.

When I saw Mrs. Cook, she was lamenting her failure to utilize services sooner. She explained that "if um...we really got going with home care coming in...they could have helped a lot and I might've had him home for years yet."

Why was it so important to Mrs. Cook that she manage without formal assistance in the care of her husband? Given her acceptance of formal support with her mother's care, and her satisfaction with these services, her refusal seemed particularly puzzling. It was this question that guided my reading of Mrs. Cook's story.

The Experience

Mrs. Cook's husband has been ill for over five years. When asked what it was like for her living with a memory impaired husband, she began by discussing the onset of her husband's dementia - effectively diverting the focus of attention from herself and onto her husband. This focus on her husband was maintained throughout the majority of both interviews.

Mrs. Cook indicated that it was her husband who first began to realize that "something was wrong". He began complaining that he was having difficulty performing in his position as an accountant related to poor memory and difficulty concentrating. He sought medical treatment and, after a one month inpatient assessment, was diagnosed as having Alzheimer's Disease. Following the diagnosis, Mrs. Cook too began to notice the changes in her husband; for example, her husband was forgetting things and could no longer read or sign his name. She noted that "all of a sudden you realize that you're taking on more and more things because he forgot to do them".

However, although Mrs. Cook was intellectually aware of the problem, the critical turning point in her realization that something was `really wrong' seems to have been when her husband failed to recognize her. After matter-of-factly outlining the above changes, she stated that "the first indication I had that his memory was really going was one night, he looked at me and asked me who I was". At this point in the interview, she began to cry for the first time.

Throughout both interviews, Mrs. Cook returned repeatedly to her husband's lack of recognition of her as a particularly painful aspect of the experience. Sometimes she spoke with puzzlement - "you just can't figure it" - while at other times the distress was evident in her voice as she acknowledged the fear that this raised.

I interpreted the significance of this symptom as being grounded in the questions that it raised for Mrs. Cook about her identity in relation to her husband. In particular, her sense of self as `wife' was challenged.

> ...he didn't, like I told him I was his wife but he didn't believe me, so one night he didn't want me to go to bed because he said I was a nice lady but he wasn't that kind of a man. So eventually, I moved out of the bedroom.

Mrs. Cook initially discounted the significance of this change; she pointed out that because of her husband's unrest she had not been getting enough sleep when she and her husband did share the same bed. Moreover she noted several times that they "hadn't been living as man and wife" for quite a few years. However, later in the interview, she addressed the loss of physical contact that this move precipitated.

We hadn't had an intimate relationship for um, quite a few years - I don't know

whether it was from that or the medication he was taking for his angina, because I understand some of that medication can affect, so the fact that we slept together was just, it was nice to have a warm body there, to hold you know, or put your arms around somebody or something like that, but um... [voice fades off]

.....during the night and that if you're cold there is somebody there; you notice that if you're sleeping alone. Other than that you're sharing pretty well, just as you've always been. It's just well, no hugs and kisses. So you gradually get use to that not happening. And...I guess you miss it but you don't think about it. Too busy.

She concluded by acknowledging that her special status as `wife' to her husband was "all gone". Rather, her role in relation to him had to be renegotiated.

I tried giving him pictures to look at and at the first, I think he knew, without really knowing if you know what I mean, you're showing him proof but he wasn't really accepting it, but then he got so that he didn't even recognize pictures of himself, so of course, he didn't recognize it was me, because well, you change over the years, so that didn't work. So gradually, it drifted into a situation where he accepted my being here to look after him because he admitted that he didn't know how to do the wash, or the cooking or the cleaning, and he needed help. So he would, if something nice happened that he thought I did, he would call me his very nice friend

Later she summarized the caregiving process by defining the roles she had played

in relation to her husband:

> Well, I guess I figure we were more or less like a normal married couple, we had our ups and downs and stuff like that, and then, I became more a companion and then later I guess maybe more um, a housekeeper and then gradually more a nurse than a housekeeper...and now... I feel lost.

In this relationship with her husband, Mrs. Cook defined her `success' in terms of her ability to attend to all of his care needs. This included: assuming all homemaking tasks; taking care of his physical care needs such as toiletting requirements, bathing and feeding; insuring that "he had something to do and...fill the hours one way or another"; and, perhaps most difficult, overseeing her husband's emotional well-being. In particular, protecting her husband's self-esteem emerged as an organizing principle which seemed to guide her actions; she summarizes her response to his disease by indicating that "I gradually took over more and more and more and trying to keep him from noticing that I was doing it."

> I at first compensated I guess, um when I noticed he was forgetting things, if I noticed it was a specific thing, I would try to avoid that, um, I don't know of course whether that was the right thing to do or not?....I would make excuses too. Like he started having trouble signing his name and I would just sort of laugh it off because he wasn't doing much writing any more, or else um "you don't sign your name hardly any more at all"....And I would make excuses to him if he would see I was doing something. I always tried to not get him upset about something. I would tell him that all people notice a change in their memory as they get older, and to not worry about it.

She provides numerous examples where her actions are developed with the goal of preserving her husband's sense of competence and control. Reading about the disease for example, is done while riding the stationary bicycle in the basement because she knows her husband can no longer physically handle the stairs. Similarly, Mrs. Cook discusses her attempts to insure that her husband was unaware that she had taken over the finances. These included obtaining a duplicate account book for her husband to carry and insuring that he always had some money although she knew it would be lost.

> He had been carrying about $300 dollars in his wallet so I gradually kept taking another $20 dollars, then $10 dollars so that he wouldn't notice the amount decreasing. I got down to about $100 dollars and then left him with that because I figured you have to have enough bills that you can count in there. Although he got to the point where he couldn't count them.

Gradually, because he could no longer count

> ...he would carry change in his pocket but he wouldn't use it. If something was $4.50 and he had two two dollar bills and fifty cents, he wouldn't give them that, he would give them $5.00 or $10.00. So, gradually he ended up with all this change. So I started buying it off of him and give him a bill for it. I'd say, well, I needed change for something to get some of it away from him.

Regarding her actions she indicates that

> the only thing that bothered me the most was that he was going to find out what I was doing, because I didn't want to upset him.

She talks about making problematic items "disappear" gradually - old clothes, the wedding

band that he kept misplacing... while simultaneously insuring that these items remained "handy" in case he asked about them at a later date so that he "wouldn't get upset". The balancing act associated with this was identified.

> Like he left his wallet he went into the bathroom he takes everything out of his pockets. And if I would go in afterwards and his wallet was laying in there, do I tell him that I found his wallet in the bathroom or do I leave it there for him to go in and find. You always have to make that decision at the time. Like is he going to be upset because he forgot his wallet. Or is it better if I let him find it instead of saying, "look, here's your wallet, you left this". So each time you have to decide. I found it stressful. And what would work one time wouldn't necessarily work another time. So each day, it's a new decision. Like you know "what do I do now" "what do I do now" "what do I do now".

Caregiving is seen as a complicated balancing act between doing what needed to be done, while preserving the facade that nothing is changing.

While the need to protect her husband seemed to arise from the altruistic motive of providing good care, I began to question the degree that self preservation also played a role. As `no longer wife' Mrs. Cook expressed considerable uncertainty regarding her role, the situation and what she could expect from her husband. I was struck by the frequency that this uncertainty was described using "fear" words. For example, after referencing her husband's lack of recognition as "scary", Mrs. Cook elaborates:

> um, when there are just two people in the house and you know the other person

doesn't want you there, you don't know if should I do this, or should I do that? Um, because he would question, say I wanted to throw something out, or move something, why was I doing that because it wasn't mine...so you are constantly on edge.....and **although he never was physical or anything, you don't know, in the back of your mind whether he could be or not.** Because he could have a personality change. He always was very quiet and compassionate and not prone to be physical but you're not sure whether he could be or not. You're just... on edge all the time. (emphasis mine)

This renegotiation of her role, took place within a context of uncertainty and isolation. Throughout both interviews Mrs. Cook repeatedly referred to her perception that "you never knew what to expect". She acknowledges that

> ...neither one of us knew much about Alzheimer's so when they say somebody has Alzheimer's you don't really know what to be prepared for and it kind of scares you I guess. So I use to say, whatever it is, we'll just see it through together, you know and...you just go on. And...the time goes and you don't really think about it one way or another - or else ignore thinking about it I guess is closer.

However, despite this stoic resolve, the tension inherent in this uncertainty was apparent. At one point during the interview as she began to sob quietly. "You're sort of on egg shells all of the time...will I do this, or that, or say this..." This uncertainty is directly related to her husband's unpredictable behaviour; in many ways he is like a stranger. She indicates that:

> But it's just, you never really relax because he could be talking about something and

then just, all of a sudden sorta "who are you?" as if he'd just walked into the room, as if he hadn't been talking to you. **You never know what they're going to do next.** [emphasis mine]

I guess I wanted to know where I fit in so I'd know how to react. Um, it scared me, of course. And you can imagine if somebody looked at you and didn't realize who you were it gives you a real jolt. But then the fact that he wanted me out of the house bothered me because I didn't know really how to cope with that, he was going to..oh he locked the door a couple of times and then questioned me when I came back in because he wondered how come I had a key. Well, it was more um..um..I didn't know how to cope or how to help him if he locked me out.

As Mr. Cook's need for help increased, Mrs. Cook's life became increasingly focused on responding to him. Seeming to distance herself from the relationship, she describes feeling "in a way, where um..your whole being seems to be what to do for them and how to go about it so you don't upset them in any way". She gave up many former interests and routines - for example she stopped attending church, discontinued her monthly dinners with a group of friends, and even declined to attend her only daughter's wedding because she felt uncomfortable leaving her husband.

Even after her husband was hospitalized, Mrs. Cook describes him as her "focal point" and indicates that her day is structured by his feeding times.

it's strange, I guess, people go through it, maybe they've lost their mate, but when I get up in the morning, I have nothing that really has to be done that day, except going

to feed him [begins to cry]

Later she indicates that

I put feeding him, I guess.. I guess the social worker's trying to start up a support group but there again, I won't go to it unless it's at a different time when I don't have to feed him.

Although Mr. Cook no longer recognized her as his wife, it is mainly through his eyes that she was seen at all. Mrs. Cook identified the value of her husband's gaze; she suggests that it is only because of his response, albeit unpredictable and infrequent, that she retained her feeling of being "human".

Even now sometimes, like I don't know what he's thinking but he'll go like that or pat my arm or something as if he's concerned, I don't know what he's saying.

She expressed uncertainty regarding whether her husband was responding to her specifically, or whether he had similar reactions to all strangers. Regardless, these brief moments made her feel that "there's lots of people worse off". However, these moments of responsiveness from her husband also served to further restrict Mrs. Cook's experience of herself. She acknowledges the need to restrain herself from displaying negative emotions. For example she felt unable to act upset when her mother died because "although he didn't know I was his wife, if I was upset about something, or started to cry, he would get upset".

Sometimes, it appears that the need to be seen outside of this relationship did surface. This desire however, was quickly disavowed.

Well, I use to once in a while, say it would be nice to go someplace and somebody knows who I am. [laughs] You know...No, it...things happen and you just accept it

and work with it or around it and you get use to doing that and I never stopped to think about it. And I just kept getting more tired and more tired...

This `reconstruction' of Mrs. Cook's experience raises critical points. First, Mrs. Cook's sense of who she is in relation to her husband is disrupted. Specifically, with his increasing dependency on her, coupled by his lack of recognition of her, she is forced to redefine her position as `wife'. She assumes a new subject position as companion/housekeeper/nurse. Her primary sense of self seems to arise from this location and it is in this position that she judges herself. Second, this position is assumed within a context of uncertainty and isolation. In other words, it is not a safe, or comfortable position and she is dependent upon the unreliable validation and affirmation from her husband.

Ironically, although she no longer saw herself as `wife' it was from this relationship that the obligation to care originated and remained; she clearly expressed her belief in the sanctity of marriage and saw herself as having no choice but to "take care" of her husband. "I guess I figured that's what a wife does" is how she described her sense of responsibility. In fact, upon reflection, she notes that even before his illness "I guess, I always, sort of....did...do..what I thought was best for Paul". In other words, the caregiving role was seen as simply an extension of her role as wife; a more exaggerated form of taking care than she had historically provided in her relationship with her husband.

The assumption of this role was non-negotiable. Mrs. Cook stated clearly that the only time that she believed a wife could possibly consider not providing care to an ill husband was if the husband had historically been physically abusive with the wife. Since Mrs. Cook's husband had loved her, perhaps more than she had loved him she notes twice,

she perceived herself as obligated to look after him.

The implications of this are twofold. First, because it is grounded in her role as wife, Mrs. Cook's perception of her self was at stake in her ability to take care of her husband. Second, as an extension of her marital responsibilities, her position as caregiver remained a private role carried out in the private setting of home. This situation appears to have had strong impact on Mrs. Cook's perception of the use of formal support services.

The Meaning Associated with Service Use

Although formal `support' services are ostensibly `supportive' to caregivers, Mrs. Cook's experience makes visible a number of alternative interpretations associated with the use of these services. In particular, three inter-related meanings are suggested by her story: service use as fostering a sense of redundancy; service use as disrupting a precarious balance; and service use as problematizing the caregiver.

Mrs. Cook's primary sense of self stemmed from her role as caregiver. This was the only legitimate role that she identified as available to her and she spoke openly and hopelessly about the lack of meaning in her life beyond her relationship with her husband. This relationship depended upon her `taking care' of her husband and this was clearly interpreted as providing both concrete and emotional care. Given this, I queried that services might be seen as a threatening this status, and hence the very core of her sense of self. Certainly following her husband's hospitalization she described the pointlessness in her life and referenced herself as "lost"; within a month of his subsequent death, Mrs. Cook suffered a massive stroke. Service use then may have subconsciously been recognized by

Mrs. Cook as endangering a vital source for making meaning in her life.

This explanation however fails to recognize the double-binds associated with using services for Mrs. Cook. These centre around the conflicting positions in which Mrs. Cook is being placed.

Mrs. Cook's first mandate is to sustain her husband's personhood. As noted, a central theme to her story regarded her need to organize her activities around protecting her husband. This need to protect him is cited as the main reason that she was reluctant to utilize home support services. For example, although Mrs. Cook expressed considerable anxiety about leaving her husband alone, she refused to access home support services. She indicates that "I thought it would hurt his feelings too much.....Well, how do you tell someone that somebody is coming in to babysit you because I am going out?" Rather than distress him, she preferred to limit her absences to those errands that were vital for survival, such as grocery shopping, and then race through these activities as quickly as possible. Always in the background there appears to have been an invisible, but complex, weighting process going on as she tried to evaluate the potential risks of harm during her absences against the damage that would be done to her husband's self-esteem were she to accept services. Support services were seen as a viable option only when the risk of physical harm became too great; in other words, they were a last resort. Mrs. Cook was quite clear that she herself would derive no benefit from services if they "upset" her husband. The first double-bind then is related to Mrs. Cook's attempt to protect her husband both physically and emotionally when his emotional and physical needs required different strategies.

At a broader level, Mrs. Cook's story makes explicit the contradictory positions

between taking care of her husband and managing the situation. She described her ongoing experience as a `balancing act'. She repeatedly referenced the continuous tension between protecting her husband's personhood while simultaneously taking over the situation. The two are incongruent and the stage is set for Mrs. Cook to feel like a failure irrespective of what she does. As woman and wife, Mrs. Cook's feeling of competence will be reflected by her ability to `take care' of her husband; this means empowering him. However, as caregiver she is expected to take control of the situation which requires that she exert power; the caveat is that this must be made invisible. Unless she can successfully achieve these two conflicting goals, Mrs. Cook is set up to feel guilty.

> ...the first couple of times I signed cheques and that, I felt guilty, because well it was his money. But then I would think, well, it is my money - I don't have a job, it's up to him to pay to run the house. So his money is my money. But I would still not...if I wanted something for myself, clothes or that, I wouldn't buy it out of his money....Even when I started having the lawn men come to do the lawns and that because he wasn't able to, I paid for that. Because at first he was upset if I went out to cut the grass or anything because it wasn't my lawn. I didn't have to do that, but of course he couldn't do it. Well then he...more the feeling that he should be out there doing it, that I shouldn't be doing it. So he got upset about that. So it just became where garden work was a real chore because he didn't want me to do it. So when I got help for the lawns, then, I paid for that [out of a small personal savings account accumulated from her own part-time work activities several years earlier] because I figured well, it was kind of my fault because I'm not out there.

This example highlights the delicate position from which Mrs. Cook is operating.

From this perspective, the potential for support services to further disrupt a precarious balance becomes clear. Mrs. Cook voiced her expectation that her husband would object to the use of services. To utilize these services then, would require that Mrs. Cook contend with her husband's objections. In other words, not only would she need to risk damaging her husband's sense of self, but additionally it would be her responsibility to deal with his reluctance. This confrontation would take place within a context of being unable to anticipate her husband's reactions which contributed to an ever-present, underlying fear of violence. Even without this threat of violence, the least Mrs. Cook could expect were she to use services was that she would be required to spend time settling her husband; a situation in which she felt very vulnerable.

In this equation there is no place for Mrs. Cook's needs. "I honestly don't know where I fit" she sobbed quietly when asked directly about her own needs. Generally, her definition regarding what was acceptable was based primarily upon her husband's needs and not her own. This situation did not change until her own health was endangered and then as soon as she had recuperated slightly she berated herself for not lasting longer.

Given this situation, not unexpectedly, services could not readily be defined to meet Mrs. Cook's `needs'. The strongest `need' she had was to avoid disrupting the situation. For example, she refused to consider the idea of utilizing a respite program in order that she could have some time for herself. She noted that:

When I talk about it, I figure I sound like some kind of martyr (laughs) but it doesn't

feel that way...It's just best if I do this right now, because it's, not...upsetting anybody. You have to live with yourself. You have a conscience. If you go out and are enjoying yourself and something bad happens while you're out, how do you live with it?

Another issue complicated the identification of `personal' needs. Because her work evolved out of her role as wife, Mrs. Cook discounted many of her caregiving efforts as simply `what a wife does'; as a result the extra work associated with caregiving was not visible. She disclaimed compliments regarding her efforts by normalizing her actions as simply what was "expected" of her. For example, as noted above, Mrs. Cook could articulated the many elaborate attempts she made to manipulate the situation in order that her husband would be less aware of his problems and would feel "as if he was, well, still in control, I guess". This work however, was not acknowledged and in fact, Mrs. Cook responded with puzzlement, when I pointed it out: she dubiously conceded that I could describe her actions as ingenious... but *she* would describe her actions as simply insuring that her husband "wouldn't realize he wasn't doing it I guess". Similarly, she attempts to normalize her entire situation:

um...well you...it...it's like everything else. It goes day by day and you accept the next problem. And it fits in, like doing a puzzle I guess. And you work around that one.

Living with a spouse who suffers from Alzheimer's Disease and taking responsibility for meeting more and more of his care needs is relegated to the status of "just like everything else". In this scenario, one does not require formal assistance in managing `normal' day to

day activities.

Interestingly, recognizing the amount of work that she was doing may have placed Mrs. Cook in a double bind. Specifically, it was only once the situation had deteriorated to the point where she required treatment for depression that Mrs. Cook could acknowledge the strain of her caregiving. "I wore out" she admits. Her needs in the situation could then be acknowledged. However, another reading of this is that only when she could no longer cope did the amount of work that was required of her become noteworthy; in other words, it only became visible because it was not being done.

This sets the stage for the use of services to be associated with inadequacy. When initially asked about her reluctance to utilize services she responded by indicating that "I was handling it myself". Later she acknowledged that services had been suggested "but I didn't think I was having a problem. We were coping alright". In these statements Mrs. Cook presents service use as a viable option only if you are experiencing problems which you are unable to manage. However, she also raises another critical issue: How is one is to recognize a problem? Defining a problem appears to be closely associated with her ability to cope and not her husband's condition. Only by not coping does a problem become visible, as long as she is coping there is no problem. In other words, she implies that in order to use services she has first to define herself as deficient. She must own the problem not her husband.

Although the dominant meaning associated with the use of services by Mrs. Cook was that she had failed, Mrs. Cook voiced some resistance to this. The struggle between perceiving herself as deficient, and therefore requiring assistance, versus the recognition that

the situation was unmanageable, in which case services wouldn't help, is seen throughout Mrs. Cook's narrative. For example, after discussing the problems she was experiencing assisting her non-compliant husband with toiletting, Mrs. Cook concludes by suggesting that

> I guess you try different ways to get through to them, well, [demonstrating what she would say to her husband] "You're here, you have to go" kind of thing. And nothing, nothing works. So you keep thinking that it's you. That there is some way to get through and you can't find it.

With this statement, Mrs. Cook locates the problem within herself - she isn't doing it `right'. This perception arises from her belief that as `caregiver' she should be able to cope better with "them", the patient. However, when Mrs. Cook repositions herself as the subject "I" attempting to deal with "him" her husband, she begins to question this interpretation. Talking about the same problem, later in the interview, Mrs. Cook discusses the possibility of receiving help from home support services.

> so every time he had to go to the bathroom, I couldn't have somebody [referring to home support worker] come in the house and then he wouldn't, he wouldn't go for them. It's even worse than trying to go for me because the homemaker tried to get him cleaned up the one day she was here and he was just hollering at her. It was worse, because she was a stranger. Now they said that maybe if somebody, if the same person especially came in all the time, he'd get used to them but to me, that didn't make sense, he saw me everyday and he wouldn't let me, you know. So if somebody else came in for a short period every day, I'm sure he wouldn't have co-operated any more with them than he would have with me.

In this exchange, Mrs. Cook seems to be questioning the perception of herself as inadequate. Rather, an alternative reading - that the situation is out of control and that services would not be helpful - appears to be surfacing. This positioning still however fails to situates service as `supportive' . Rather, the involvement of a homemaker is perceived at best as inadequate and futile. At worst, the homemaker is viewed as an opponent; if Mrs. Cook's tentative interpretation that perhaps the problem does not lie with her is to be supported than the homemaker's attempt to help must fail.

In summary then, Mrs. Cook's story begins to highlight some of the alternative meanings that can be associated with the use of services. Her story suggests that although the experience of living with a memory impaired husband may appear to be oppressive and damaging, there is nevertheless a sense of self tied to the position that may be threatened by the use of services. Her story also highlights the precarious balance associated with caring for a memory impaired husband related to the conflicting demands and suggests that service use can easily be seen as disruptive rather than supportive. Finally, her story demonstrates how service use can problematizes the caregiver's response by becoming an option only after one is no longer able to cope.

Conclusion

Mrs. Cook's story raised three important issues for me. First, her story drew my attention to the importance of recognition by one's partner. Of all the symptoms exhibited by her husband, it was his lack of recognition that forced Mrs. Cook to realize that something was "really" wrong. Simultaneously it is her husband's recognition that is

identified as crucial to her for maintaining a sense of herself as human.

Second, I was surprised by the degree that Mrs. Cook seemed to internalize problems around her husband's behaviours as her deficiencies. It seemed that her initial response was to blame herself for failing to circumvent issues. The fact that her husband's behaviour is related to a disease is relegated to the sidelines.

Finally, Mrs. Cook's story points out the contradictions of being wife- caregiver and service user. Specifically, the two are posed as incompatible subject positions. Caregiving, as defined within the context of the private realm of normality for women, is diametrically opposed to service use. Specifically, as Mrs. Cook brings to light, there are certain implications associated with being a wife-caregiver. In particular, a sense of `selflessness' is associated with this function which precludes the use of service; in order to `do it right' she must have no needs of her own. Second, the work of caring must not be seen; if it becomes visible it too is a sign that she is not `doing it right'. Because of her belief in her marital vows, Mrs. Cook is unable to position her role as caregiver in any other location than as an extension of her marital responsibilities. As her husband's needs become all consuming, there is no space for Mrs. Cook to identify, let alone attend to, her own needs. If she does, she is placed in a position where she is likely to be judged (and judge herself) as inadequate.

CHAPTER 4

CARING: "I AM A PROFESSIONAL"

THE STORY OF LOUISA FORD

Setting the Stage

Louisa Ford is a 60 year old woman who has been providing care to her 90 year old husband Michael, for over sixteen years. He suffers from Parkinson's Disease and Alzheimer's Disease and has deteriorated to the point where he is curled into a fetal position, unable to even move by himself. Unlike most of the other participants in this study, Mrs. Ford has made extensive use of formal support services in her attempt to maintain her husband at home. In fact, she described herself as a problem to service providers because she has been so vocal about her demands.

Her response to services provided an interesting contrast to most of the other participants. How had she come to such a different understanding of service use? With this question in mind, I sought Mrs. Ford out to request her assistance with my study.

Mrs. Ford was quite receptive to participating in my study. Although she maintains a hectic, exhausting schedule, she felt she had important insight to offer regarding the plight of 'caregivers'. Her commitment to the process of informing me was demonstrated by her willingness to meet for a second interview "because there might be some things I've forgotten too". At points during the interview she would pause to insure that the tape-recorder was working because she was going to say something she considered significant for

me to remember. She requested a copy of the transcript as a reminder of what she had said, and to assist her in preparing for a forthcoming talk she had been asked to give. This reaction was a contrast to Mrs. Cook's who felt she had little to offer and required assurances that the research process would not deprive her husband of her care in any way.

Over five hours were spent with Mrs. Ford during two visits in her home. She lives in a large, modern bungalow in an upper middle class suburban area. The house had been modified in many small ways in order to accommodate her husband's disabilities - for example, ramps were installed, one bathroom has been converted to a medication room, and furniture had been arranged in order to allow wheelchair paths. The house was elaborately furnished in heavy, dark furniture described as `mostly antiques' by Mrs. Ford. At one end of the living room an alter with two kneeling pews had been set up. Mrs. Ford commented that the quality of the home and it's furnishings gave the erroneous impression that she was financially affluent when in fact most of the couple's savings has been spent on her husband's care.

Mrs. Ford began the interview by suggesting that first I meet her husband. After greeting him and introducing him to me, Mrs. Ford then took me on a `tour' of his bedroom. In addition to the open storage drawers containing different types of diapers, sheet pads, hospital gowns, and various ointments and creams, the room also contained a hospital bed, a ventalin machine, an oxygen machine, and a suctioning machine. In the adjacent bathroom, Mr. Ford's medication (both regular and homeopathic remedies) were prominently displayed on the counter. Beside them there were two notebooks - one monitored medication and bowel movements and the other maintained his vital signs; Mrs.

Ford required that all service providers fill in the required information and sign out. Mrs. Ford spent about fifteen minutes showing me her husband's rooms and telling me about her `system' of care and the many ways that the household had been organized in order to respond to her husband's needs.

Mr. Ford presented as a very frail, thin man whose body is beginning to curl into a fetal position. He is unable to move his limbs and has to have someone turn him regularly. Watching Mrs. Ford try to move her husband's arms, it was evident how stiff he is to move. His skin tone was excellent - Mrs. Ford proudly pointed this out by showing me his legs and feet - and he was clean and well-kempt. Mr. Ford is tube fed and requires oxygen. While I watched, Mr. Ford did not communicate in any intelligible way that I could see - rather he stared ahead or closed his eyes, and his facial features were fixed. In contrast to my impression however, Mrs. Ford spoke warmly about the many ways that she felt he communicated with her; noting for example, the way his mouth curled into an "ooh" when he was feeling satisfied or how his hands would clasp hers at night and not want to let go. Mrs. Ford indicated that these brief moments where she felt her husband responded to her were very important to her.

Mrs. Ford's interactions with her husband were interesting to observe. Several times she directed her attention solely toward him, telling him that he was a `good man' and that she loved him. After these interchanges, she turned to me and explained what she was doing and why - for example, highlighting the importance of talking to the `patient'. The impression given to me was that she was modeling behaviour in order to teach me. Similarly, when she repositioned her husband's arms by talking to him and slowly moving

them back down, she questioned whether I had noticed what she was doing and then explained her technique. She always spoke in a bright, positive voice to her husband and supplemented her words with touch.

Background

Mrs. Ford is a smallish woman of medium build. She presents a tidy, practical appearance. When I visited she was dressed in a clean sweat shirt and sweat pants and orthopaedic-like sandals. Her dark brown hair was done neatly in a french twist and she was wearing make-up. She looked much younger than her 60 years and although she complained of chronic exhaustion, in fact she looked well-rested, healthy and vital. (Mrs. Ford later noted that her physical appearance was frequently incongruent with her emotional state.)

Unlike Mrs. Cook, Mrs. Ford provided considerable information regarding her background. She used this information to situate her current sense of responsibility for caretaking. Moreover, she clearly valuated this aspect of herself.

> I'm a child of the 30's. The Depression years. You worked. You grew up fast. And you had to sort of earn your salt. So, we all worked very hard and as a child, we were seven children in the family but to survive in those days, my mother had 32 boarders and seven children and she really worked. So we worked, we didn't have time. And I was the oldest girl. So even at three years old I was busy. I was buttering bread for the lunch of the men at 5:00 in the morning. Not that my mother woke me up or insisted, it was just something in me, I would wake up because I heard her in the

kitchen and it just, I just felt I should go and keep her company and be with her because she was preparing breakfast for the men and doing their lunches. I would sit in the high chair and she would give me the bread near the counter and I'd butter the bread so she could make the lunches.....When I was seven, I was cooking supper. I stood on a chair at the stove and cooked supper. My mother had to cook supper for the boarders and I cooked for my family.....And that was, I don't think maybe I would have been able to cope so well had I had everything rosy and velvety when I was a child...Because at 14 years old I worked in a private home after school and on weekends. I also worked in a..a.. women's clothing shop and I was so good that at the time I had clients that would drive 90 miles just to come and see the new clothing we had received. I had an `okay' to phone them collect and tell them we had a new shipment and I knew what would suit them. And I never lied to them. If I didn't like something on them, I'd tell them, quietly, not in front of the owner. I would just go sideways, we had a little signal and I'd say that's not for you. But you see I grew up being responsible. And we were expected to clean our bedroom, make up our beds and mop our bedrooms, empty the garbage, do the dishes, when we were seven years old we were washing dishes, cooking, all of us.. And we can expect that from our children and if we don't, we wait until they're ten, twelve, it's too late and then we have children who are bored because they don't know what to do. Then we learned to knit, we learned to crochet, we learned to sew as well as cooking. See, today our kids don't know any of these thing and they, they have too much time. And we also had to read, we had to have reading time. We didn't have TV but we had to read.....

It made me very resourceful.

Using her background history to define herself, the potential for Mrs. Ford to position the giving of care as not simply a private activity, begins to emerge. Specifically, her earliest recollections revolve around her mother's provision of care for profit. Simultaneously, Mrs. Ford situates the giving of care within the context of relationship building; her means for obtaining closeness with her mother is to assist her in the provision of this care. Later, Mrs. Ford positions her own caregiving activities within the context of public reward. She also makes explicit her association of being "responsible" with the provision of empathic care.

Mrs. Ford indicated that she obtained a college education and then taught - initially in Northern Ontario, and then in Toronto. She left her teaching position when it became too dangerous to leave her husband alone because of his illness; he was wandering and on one occasion, started a fire in the kitchen while she was working. Mrs. Ford felt she would never gain re-entry into the teaching profession given her age and the scarcity of positions and worried about her future financial security.

Of all the women who participated in this study, Mrs. Ford was the only one who worked in a professional position. She referenced her teaching experience as having been a valuable asset in her caregiving role and frequently expressed the requirements of her role as caregiver in the language of teaching.

I had to learn how to help him. But my background is teaching, so I guess a lot of these things came to me too.

This seemed to give Mrs. Ford a lens for viewing her position as caregiver that was based in a recognized, visible profession. This was in contrast to all of the other women in this study who were more reliant on the language of love and obligation for defining their positions.

Mrs. Ford met Mr. Ford while staying with his relative. At that time, Mr. Ford was married and raising a family. Mrs. Ford spent one summer working for the Fords then returned to teaching and lost contact with the Fords. Several years later, upon hearing of the death of Mr. Ford's first wife, Mrs. Ford re-initiated contact by sending a sympathy card. Mr. Ford began visiting her periodically and then quite unexpectedly, asked Mrs. Ford to marry him. Mrs. Ford initially agreed to the marriage because "I didn't want to hurt his feelings" and then "gradually came to realize how much I loved him".

The couple were married when Mrs. Ford was in her early forties and Mr. Ford was in his seventies. Although she describes the first year of her marriage as very happy, in retrospect, Mrs. Ford suspects that her husband may have already been ill when they married.

The Experience

When asked what it was like for her living with a husband who was memory impaired Mrs. Ford responded that:

> What he... it's very important for the caregiver to remember, or to be told or taught that it is the disease that creates the change in the person and not uh, it's not the person, that oh well, he was difficult before, or she was difficult but that's, that may

be so but the illness certainly has something to do with it. And in a case like that where the person may have been difficult before the family member or the caregiver has a harder time to recognize what is disease related and what isn't.

With this response, Mrs. Ford introduced one of the critical struggles for her when her husband first became ill - the struggle to depersonalize her husband's symptoms. Identifying this as "very much" an issue for her, she spoke of her initial reaction to her husband's symptoms.

Like the first time we were out with friends having dinner and um, it was a dinner party and he suddenly said well "where's my wife?" And we all thought he was joking. I said well "I'm here darling". He says "no, no, you're not my wife, you're not my wife". Of course we hadn't been married all that long and I though "Oh my God". And I'm his second spouse. I felt like two cents, I thought maybe they think we're not married and I wanted to crawl in a little corner and I suddenly felt very much ashamed, I didn't know what was coming on. And uh, many times afterwards when he would hallucinate at night, he'd want me out of the bedroom. That was very, very hurtful.....I thought maybe my husband didn't love me any more. And I thought maybe his children or somebody in the family would have convinced him not to love me. You see, I was a second spouse, it's really different.

Like Mrs. Cook who took her husband's lack of recognition of her quite personally, so too did Mrs. Ford feel personally deficient at the onset of her husband's disease. She

wondered what was wrong with her. However, Mrs. Ford portrays herself as having fought this interpretation. Even as she talks about the hurt she felt over her husband's lack of recognition, she immediately asserted:

> But I just knew that there was something wrong because my husband had been such a wonderful, loving, caring, patient and generous husband - like to him I was his queen.

> I just knew that it wasn't my husband, after a while I realized it wasn't my husband, it was the disease.

At no point during her story did Mrs. Ford ever express anger at her husband. Rather, her two options were to either blame herself or to assign responsibility to the disease. Even when Mr. Ford went through a very aggressive stage during which he was physically violent with Mrs. Ford, Mrs. Ford suggests that "I knew it wasn't him" because "when he came back to his senses he was so loving and gentle". The implication was that because it wasn't `really' her husband, it was her responsibility to deal with his behaviour.

> And he pulled out a whole handful of my hair. I still have it. And he had torn my gown. Because I was trying to hold him, but I did not know how to do it, see, I was just learning.

Given her certainty that "something was wrong" Mrs. Ford described the trying process of attempting to obtain a diagnosis because "it was driving me crazy". Her pursuit was carried out over her husband's objections.

My husband, when I had to take him to see a doctor, he'd say "you're ruining our marriage, you're ruining our marriage". And I'd get there so upset I needed the doctor more than he did. But I just knew we had to do something.

She then grounded this sense of certainty in an extensive narrative about the problems her husband was having; as if she was required to vindicate herself that it was neither her intention to destroy the marital relationship nor were her motivations selfish. Additionally, she offered her insight into her husband's reluctance as being founded in his embarrassment about his deterioration.

Because her husband's condition was complicated, determining what was actually wrong was a lengthy process. Mrs. Ford identified this "not knowing" stage as the most difficult aspect of the disease process. She was frustrated by inconclusive assessments and descriptive medical jargon which meant nothing to her. Treatments were tried that only aggravated the situation.

Obtaining a diagnosis is presented as a critical turning point in Mrs. Ford's experience. It freed her from holding herself responsible for the changes in her marital relationship. Rather, she could assume an `it's not me position" by blaming something external. It also provided her with a direction. Specifically, once a diagnosis has been obtained, Mrs. Ford then sought information in order to develop some understanding of her husband's symptoms and obtain ideas for treatment. Repeatedly, she highlighted this as a vital step for `caregivers'.'

That's why it's very important for, I think it's, it's really important to know

something about the symptoms - ah, what might happen. It doesn't mean that every person will have the same symptoms, but if you know something about it, somehow psychologically you adjust to an extent. You're prepared a little bit. It doesn't come as a shock. And you don't take it as personally.

At only one point did Mrs. Ford allude to the difficulty of achieving this stance. In passing she admitted that "there were times when I wanted to hit him back because he was hurting me -it took me a while to realize that it wasn't him that was hurting me it was the disease that caused him to do these things". She acknowledged that "you do the wrong thing" while learning to differentiate between the two. Interestingly, at no time did Mrs. Ford credit self protection as a relatively `normal' response when someone is trying to hurt you. Rather, she consistently framed her response to her husband's condition and particularly his violence, as one of concern and learning what to do. I saw this as an expression of Mrs. Ford's perception that it was her responsibility to keep her husband functioning within the relationship.

For Mrs. Ford then, the initial experience of living with a memory impaired partner revolved around learning to assign blame to the disease rather than herself for her husband's behaviour. This was promoted by obtaining a diagnosis - which clearly identified the problem as outside of herself - and then developing a sense of competence by extensive reading and research.

In addition to this quest for knowledge, Mrs. Ford also turned to "God" to help her cope. Mrs. Ford described the importance of her spirituality; she remembered asking God

for direction at times when she was most frustrated and praying to him for a "ton of patience, not just a bucket". She credited God with answering her prayers and telling her what to do during the many occasions when she felt she was in over her head.

The Meaning Associated with Service Use

Mrs. Ford described a turning point in the caregiving process, where the use of services took on new meaning. Specifically, when Mrs. Ford initially approached services, she had not yet made the decision to keep her husband at home. She was having difficulty managing and was hoping to obtain some relief from formal support services. Simultaneously, she was considering placement options. Help seeking was positioned as a desperate last resort motivated by the concern of friends.

This experience is remembered with disappointment and anger. Despite her husband's physical aggression and wandering, Mrs. Ford indicates she was initially turned down for in-home support services; she believes this was because she was seen as insufficiently `needy' from a financial perspective. Likewise, community respite was unavailable as well because there were no day programs willing to take her husband, and the only nursing homes she considered suitable would not accept him because of his aggression. Ironically, Mrs. Ford's `responsibility' for her husband was turned back onto her because the `professionals' could not manage her husband.

She responded. Confronted with this lack of alternatives, Mrs. Ford remembers consciously deciding to maintain her husband at home. In contrast to her earlier description of taking on the care of her husband as a "gradual process, I didn't just wake up one day and

decide I'm going to take care of Michael", this decision is presented as an active determination. Specifically, she dated her explicit positioning of herself as a "primary caregiver" which "to me it's a profession" to this decision. Taking on this position required that she accept help. "People don't expect a nurse to work sixty hours without any rest!"

Mrs. Ford noted an initial reluctance to use home support services "because they usually end up ruining your house. You have no privacy what so ever."

> Uh, I think, but the biggest thing is the privacy, they know your entire business. And then they don't see you, they become familiar because they see you all the time uh, if you say, take time to rest, you read the newspaper, they're there, you feel guilty. You feel that you should be working again and you know, sometimes, I'm so tired in the morning it takes a long time to get myself going in the morning.. I'm very stiff in the morning, I often have headaches, and often I don't want to get dressed right away because I have other things to do, I have to give him a shower and then when I give him a shower I get wet too. So I don't dress right away, but that makes me..feel guilty in a sense you know, what are they going to think? You know.

In essence, Mrs. Ford recognized that by accepting services, her private life became public. All of her actions became open to scrutiny. In doing this, she identifies some concern that she will be negatively judged

However, after weighing her alternatives, this `inconvenience' is established as a necessary means for meeting her primary objective.

> And then I had to sit down and analyze the situation and decide what my options were. Either I had no help or I had, that is the price I had to pay to keep my husband

comfortable

Mrs. Ford began to identify the use of `supportive' services as having the potential to `support' her in her role as caregiver. Services were seen as promoting her ability to provide good care. "Respite care" for example, was reframed as providing her with the opportunity to attend to necessary tasks such as grocery shopping and obtaining medical supplies; Mrs. Ford denied that *she* had ever received any personal `respite' from this service! In other words, Mrs. Ford was quite clear that her use of services was based strictly upon her husband's needs and not on her own, and in fact, noted the cost of her personal freedom as the price she had to pay to help her husband.

This perception of services as a potential supplement to her efforts differed from Mrs. Cook's association of service use as threatening. Contrasting and comparing each woman's story, I explored how these differences could be understood. Several issues emerged.

First, like Mrs. Cook, Mrs. Ford had a clear identity as caregiver. However, unlike Mrs. Cook who saw herself as isolated, Mrs. Ford had a strong affiliation with the group 'caregivers'. As a member of this group, problems could be externalized rather than being perceived as subjective failures. For example, Mrs. Ford indicates that one of the reasons she became politically outspoken was because when talking to other caregivers' "the same problems kept occurring - the people, the girls, or the men in our groups were saying the same thing over and over". The problems were no longer simply hers, rather they were being caused by the situation. This seems to have encouraged Mrs. Ford to shift the blame for difficulties from her own deficiencies to the problematics of the situation. She could then

get angry rather than feeling deficient.

> Being ashamed requires that one adopt the position of one who is judged. This position precludes the possibility of being the judge - the position required in order to be angry. The very practices that produce shame (being judged) also prevent the production of anger (being the judge) (Rossiter, 1990 p.236)

Being angry is a position of higher power.

Second, but interconnected to the previous point, unlike Mrs. Cook, Mrs. Ford professionalized her caregiving tasks rather than perceiving them solely as an extension of her identity as wife. In fact, she had two different languages for expressing herself - the language of love and commitment, and the language of professional. In the language of love she saw herself as selflessly devoted to her husband - "my life was for him". This is at the noted expense of her own life and results in her life "being on hold for sixteen years". Like Mrs. Cook, she defends her actions by positioning them as what feels right to her.

> I always thought it was very important for me, I know who I am in terms of my husband. I do it [caregiving] willingly and lovingly. And I think if I had to do it again, I'd do it even better because now I have more knowledge.

However, using the language of the professional caregiver, her actions are moved from the interpersonal relationship into a more social positioning. Her husband became "the patient" or "our loved ones". She describes herself as a "co-ordinator, manager, administer," and "nurse" who was in charge of providing an "institution". In this position she implements "toiletting routines", "trains my staff" and "monitors medication". A

knowledge base was clearly required.

> And you have to rethink. You have to, what's the expression I'm looking for? - you have to...you have to think differently than before and it's always, you're always learning something, you're always, constantly learning and your always under stress.

This meant that her work could be named.

> You know when a patient looks good and looks comfortable, you have to realize that a great deal of effort went into that. And everybody that comes here, they always marvel at this, the condition of his skin and at how comfortable and clean he is. Well that requires a lot of planning and a lot of effort and physical as well as mental effort in doing this. And of course I take pride in it because I love him and I, I do it because I want him to feel comfortable, to experience love.

In contrast, when the work was attributed as merely an expectable extension of the role of wife, there appeared to be a tendency for it to get lost.

From this position as "professional caregiver" then, Mrs. Ford could identify a sense of entitlement to assistance that Mrs. Cook did not have. She could place value on what she was doing because she could see it!

> I wear so many hats throughout the day but no one takes account of that. And we are saving tax payers an awful lot of money. We provide a valiant service to our society, but they don't see us."

She saw herself as providing a service to the community and felt that this service should be recognized. As someone providing a valuable services she could then assert that she had needs too.

> What they [the government] don't take into account is that I provide an institution! And I do the work here! And I work but it doesn't count as work and I don't get paid for it.

> but the government sees us as being invisible, as having no needs, as not needing to eat. And I'm talking about federal and provincial and ultimately also our local municipal governments because they could do something too. When we save tax payers millions and millions, probably billions, across the province.

Although in relation to her husband, Mrs. Ford continued to perceive herself as wife, her vision of herself was not restricted to this context. Rather, she also positioned herself in relation to society at large. She could translate her caring from a private, interpersonal activity to a more public service. As a service provider, she could identify her rights and needs. Additionally, by widening the context within which to define herself, Mrs. Ford opened up the potential for additional validation and affirmation of her worth that Mrs. Cook did not have.

However, Mrs. Ford's vision of her worth was not shared within this wider context. Her story highlighted the many efforts that were taken to `put her in her place'. Mrs. Ford was very vocal about her anger regarding her involvement with home support services.

First, Mrs. Ford's expectations of adequate assistance was not met. She received no financial remuneration and in fact, because of the inadequacy of the amount of home nursing support to which she is entitled, had to supplement her efforts by hiring private home

helpers. Noting the expense of this, she argues that:

> I have to live too. I'm a human being. There should be some money left at the end of the month for me! Some weekends I have, I'm trying not to buy food...I try to buy very little meat you know. Uh..you know and I haven't bought clothes in a long time, I have to repair the house which I can't do, I've got to cut corners everywhere.
>
> If I buy anything for myself, I feel guilty. Because I know I need this money for his caregiving. And for paying the bills for this house.

Similarly she repeatedly noted the inadequacy of services which impeded her ability to do her job. For example, she complained of diaper rationing. "I kept telling them, does that mean I have to tell my husband that he can't void for the rest of the month?" Highlighting the incongruence between her needs as a service providers, and society's understanding of her needs, she notes that:

> and the government has established with their Social Workers and the doctors who work with the Ministries...they decide that they're going to have a grid, something like a grid, and these are the services they're going to provide when and if. And they think that's ideal. And, but in reality, what they're forcing us to do, they're forcing us to be like square pegs that are going to force into these round little holes that they've already prepared for us.

Mrs. Ford begins to identify the lack of control that she has in controlling her

assistance. This is perceived as demeaning and patronizing.

> We know what kind of services we need. Don't come and dictate to us and tell us, they treat us as if we're idiots, we have no minds.

Mrs. Ford voiced her frustration at the lack of respect she obtained from some service providers. She felt "talked down to" by many professionals and protested "and I've had some nurses thinking that they know more than I do - but they don't know my husband". With few exceptions, the picture presented by Mrs. Ford was in direct contrast to the more collaborative relationship that she both expected and wanted. Mrs. Ford clearly did not see herself as an equal in the caregiver/service provider relationship.

> And the other things that agencies do, like service providers do, they label caregivers', they're totally insensitive to our needs, they pretend to be...Because they label you. They call you a B-I-T-C-H or you're difficult or the problem is what you're doing. They don't seem to want to put, walk in our shoes...And they assume the role of the purse string holder.

She positions her relationship as an "us" versus "they" - clearly not a collaborative relationship.

This antagonistic relationship seemed to have the effect of dichotomizing the provision of care. I read it as an attempt to maintain the clear distinction between private and public caregiving and saw Mrs. Ford as being penalized for attempting to breach this artificial barrier.

Conclusion

Unlike Mrs. Cook, Mrs. Ford told a story about her attempt to move her caring activities beyond the boundaries of her relationship with her husband. By redefining her status as professional, her caring activities could transcend the private sphere into the more public arena. This then created a space for formal support services to interface in her private life in a way that was supportive rather than threatening.

In theory, this repositioning had the potential to promote a collaborative team approach to the care of Mr. Ford. Again theoretically, this `should' have been a desired goal; ideally formal support services are developed to bridge the gap between home and community.

However, Mrs. Ford's anger attests to the failure of this interface; she felt she was treated as an inferior, and that she became "invisible" in the process. Her story seems to expose the ambivalence associated with fusing the dichotomy between private caregiving and public.

CHAPTER 5

CARING: `DON'T LOOSE YOUR COOL'

THE STORY OF DAVE MALLOY

Setting the Stage

Dave Malloy is a 75 year old man who is physically fit and active, despite problems with elevated blood pressure. He presents as a short, compact man of medium build. He normally wears glasses; these cover the fatigue in his eyes that was more apparent when his glasses were removed. (During both interviews he indicated that he was not sleeping well). Until two weeks prior to our meeting, Mr. Malloy had lived with his wife of over 50 years, Eunice. She was diagnosed as suffering from a dementia in 1988 and prior to our interview was admitted to a nursing home because the home situation had become explosive and out of control.

Two interviews, totaling about six hours, took place in Mr. Malloy's home. He lives in a semi-detached split level home in a rural subdivision in Southern Ontario. He has lived in this subdivision since it was built about fourteen years ago, so feels well established and known in the neighbourhood. Mr. Malloy evidenced a strong connection to his home seeing it in some ways as an extension of himself. For example, upon my arrival he suggested that he show me through the house in order to understand how he and his wife lived; his subsequent tour included showing me the family photos prominently displayed throughout the home and pointing out crafts and other mementos that had been collected throughout the years by him and his wife. The house was kept spotlessly clean and neat by Mr. Malloy

who took over all housekeeping tasks several years ago - an accomplishment he proudly highlighted several times.

Mr. Malloy was quite receptive to participating in my study although he indicated several times that he wasn't sure how his comments would help me. Throughout the interview he maintained a friendly, jovial attitude and seemed in no hurry to end the interview - commenting several times that other than visiting his wife in the afternoon he had nothing else he had to do. He tended to take-off on questions, providing a great deal of detail and often using stories to make his point.

Background

Throughout the interviews Mr. Malloy contextualized his current experience with references to relevant aspects of his background. Then, once the `formal' part of the interview was finished (the tape recorder was turned off and I was preparing to leave) Mr. Malloy provided a more detailed, sequential personal biography illustrated with family pictures and personalized mementos.

He indicated that he was born in Scotland in 1919 - one of the youngest of many siblings. As a child his family began to emigrate to Toronto - "we came over like Noah's ark - in pairs" he joked. His turn came when he was about ten years old and he accompanied an older brother to Toronto. It was several months before his parents arrived in Canada and during the interim he lived with this brother and a sister.

About a year after his parents arrived, his mother's health deteriorated and she became an invalid. Mr. Malloy was uncertain of the cause. This appears to have had

considerable impact on Mr. Malloy. He referenced his mother's disabilities several times as a context for explaining both his lifelong self-sufficiency and his unquestioning assumption that he should take care of his wife when she became ill.

> I always had to fend for myself pretty well, my mother was in a wheel chair ..and uh, she died in '34..yeah '34...I had to go out to work at just turning 15 and I served my apprenticeship as a carpet weaver - then I never made any more after then. I enjoyed doing it but just circumstances, it was during the depression you know. And uh, my dad looked after my mother.

In this statement, and repeatedly throughout the interview, Mr. Malloy references the care that his father provided to his mother. This is seen as `what you do in families' and Mr. Malloy positions his response to his own wife as simply "following in my father's footsteps". Additionally, this statement was used to situate himself as someone who had always had to fend for himself.

Another seemingly significant aspect in Mr. Malloy's personal history is his experiences overseas during the second world war. Throughout both interviews Mr. Malloy spoke with pride of his experiences in the armed forces and to date, he has continued to maintain active involvement with other veterans. Among other things, he used this experience to position his own right to services; he had `paid his dues'.

Mr. Malloy met his wife while stationed in England and the two were married in May, 1943. Following the end of the war, Mr. Malloy brought his wife back with him to Canada.

Mr. Malloy indicated that following his return he suffered from stomach problems

and was hospitalized in the Veteran's hospital for at least a month. A story that he repeated several times during our interviews regarded this experience. Specifically, Mr. Malloy told how, on the advice of his previous physician, he opposed the surgery that was being planned for the following morning. He was discharged and for a period of time continued to have problems with his stomach. The highlight is when he and his wife accidentally stumbled upon a cure for his problem - oranges. Despite the expense, his wife insisted that he have an orange each day and his stomach problems subsequently were cured. Mr. Malloy displayed considerable pride that it was he and his wife who found the cure and not the physicians. Moreover, I thought this story was also used to illustrate Mrs. Malloy's willingness to sacrifice in order that his needs could be met.

By 1946 Mr and Mrs. Malloy were building themselves a home in the evening while Mr. Malloy worked for the post-office during the day. The couple moved into the house when only the basement was done and lived in relatively primitive surroundings while they completed the house. Mr. Malloy noted how difficult this was on his wife; by this time, they had had the first of their two children, and daughter, and a son soon followed.

Mr. Malloy worked only briefly at the post-office before securing a sales position in a large company. He worked for this organization until his retirement in 1979. Throughout the interviews, Mr. Malloy relayed a sense of commitment and belonging to this company. Mrs. Malloy did not work outside the home.

Following Mr. Malloy's retirement, the couple maintained an active life which involved participating in a number of Senior's groups, ongoing involvement with other veterans, and some traveling. His wife's illness however, brought a gradual halt to this

lifestyle.

The Experience

Mr. Malloy's story about his experience began at the point of his wife's diagnosis.

> I have problems with my memory now. Because this was...I guess, 1987 when Dr. Smith first said that she was, well, we were going to go for a tour. Do you want all this? [I affirmed that I wanted to hear anything he felt was relevant] We were going to go to Spain and Portugal for a three week vacation and before that Eunice had been, well, `not herself' and the doctor couldn't figure out what was the matter. He tried and tried and tried and then he finally said "well, I think that we'd better have her see a neurologist, Dr. Smith". And after the interview he [Dr. Smith] wanted to see me so I went in and she [Eunice] sat in the waiting room, and uh, he explained what the situation was..and then oh...And then he had us both in there so when we were both in there I told him, I said "well..you know, we were thinking on going on a cruise, or not a cruise, on a.. a trip" and he says "I wouldn't take this woman any place. She won't remember anything." And that was the first indication that there was anything really wrong.

This story introduces the difficulties that Mr. Malloy had in distinguishing between `normal' changes in his relationship with his wife and recognizing her symptoms as caused by a medical problems. For example, when talking about his wife's condition prior to the diagnosis, Mr. Malloy readily identified a number of changes in his wife such as increasing

irritability - "just enough to agitate you" - and forgetfulness. However, although his wife was sufficiently concerned about these changes that she sought medical intervention, Mr. Malloy passed these things off as "little things, little things... and just too numerous to remember". He maintained that there was really nothing wrong that could not be accounted for as a normal sign of aging being coloured by a relationship that spanned nearly 51 years.

> Well, you know, we've been married for 50-odd years so...these little things they don't bother you. You just take them.

In other words, Mr. Malloy could intellectually identify a number of his wife's symptoms yet did not apply this knowledge to begin to query that something was wrong. Rather he repeatedly attempted to normalize Mrs. Malloy's symptoms.

This attempt to discount the implications of her symptoms seemed to continue even after he had received a diagnosis. "And I still didn't pay much attention" he notes. Rather,

> You accepted it. I mean you can't go through life without arguing with your better half....You have to adapt to all these things. And the thing is, you're getting older and she's getting older..we're bound to change.

The "turning point" came for Mr. Malloy in 1990 while visiting Holland with his wife. Mrs. Malloy was left sitting with several wives while their husbands, including Mr. Malloy, marched in a parade. She wandered off and became lost. It was several hours before she was found miles from where she had been sitting. This traumatic episode made Mr. Malloy clearly aware of his wife's limitation. Interestingly, a response to this awareness is

the degree that others assume responsibility for Mrs. Malloy's care; Mr. Malloy frames this turning point in terms of its impact on how others respond to his wife and not in terms of a change in his own actions.

> I think that was the turning point. From then on, the women wouldn't leave her alone. She couldn't go to the bathroom without somebody following her. They hadn't realized - well I didn't know, I didn't think she was going to wander! He [the doctor] told me [the problem] but he didn't say anything about wandering.

How this experience impacts him personally is less clear. Furthermore, although Mr. Malloy presents this incident clearly, as the critical turning point in his recognition of his wife's limitations, this understanding does not remain constant. Rather, throughout the interviews he continues to oscillate regarding his understanding of his wife's behaviour. At times he attributes problems to her personality, or getting old, then contradicts himself only to later assert the normality of her actions. For example, referencing the couple's increasing isolation as a result of his wife's illness, Malloy tells a lengthy story demonstrating his wife's increasing jealousy and irritability as symptoms of the disease process. However, when asked explicitly if this behaviour was related to the dementia, Mr. Malloy promptly repositions his wife's behaviour as a longstanding pattern in their marriage; "she was very possessive, a very possessive girl" he responds. He then seems to contradict this:

> We..although she was possessive, we were never jealous of one another. We would go to um...wherever, well, let's for instance, we'd go to the conferences [related to his work]. So we'd go there and she'd be floating around all the different companies with this other fellow's wife, you know. I didn't care...never think anything about it.

Night out for the girls. There was no animosity whatsoever but she was still possessive and I didn't realize it was really that bad.

By the time he concluded this story, I was left feeling quite confused regarding whether this increasing jealousy was perceived as dementia related or not; I suspect my uncertainty reflected Mr. Malloy's own ambiguity. Furthermore, shortly before he had her admitted to a nursing home - four years after this `turning point' - Mr. Malloy indicates that

the kids were getting on my back saying "dad, you've got to put her in a home". They may have, they probably saw it but..I didn't see it, I just accepted it. It's part of living, it's part of old age coming on you know.

He concludes by acknowledging that the fact that something was wrong with his wife "never came to the forefront". Rather, at least on an emotional level, it remained largely in the background. In other words, Mrs. Malloy's illness never explicitly assumes centre stage in Mr. Malloy's story about his experience; it is off in the margins exerting covert influence that is rarely actually named but rather is repeatedly reframed within the realm of normality.

Explaining why he never really consciously thought about the changes he points out that:

my mother was an invalid in a chair so I, I was used to all this, and I didn't mind, I was retired, I didn't mind doing the house work. I do it all now. I've been doing it all for several years now. And, but then I could go out for my walks and what not but the last two years, two and a half years maybe three years, I haven't got out much and uh..lost most of our friends..

Although not clearly identified as such, the influence of his wife's deteriorating condition is pervasive. In Mr. Malloy's story, this impact is presented in relation to the couple's increasingly restricted lifestyle. It is within this context that Mrs. Malloy changing behaviours are given meaning.

> We continued to do [things together], we continued to go places. And uh..oh I don't know, it's...these things just gradually come up, you...you.. I guess it depends on the individual personality eh. You accept things and let them go and that's the way it goes. And...then she started to feel that um... Like we use to go to with the seniors down at the pool here, we used to swim everyday, like do 25,30 lengths of the pool down there. And you know, it was the business men, I guess you had to swim the lengths and you couldn't go across and you had to go the whole distance, and uh...then we'd go square dancing down with the seniors down there and uh, we square danced, we went dancing twice a month....But that carried on until I don't know, maybe...the year after [the turning point] she started saying she couldn't get her hands up and then she couldn't remember the calls square dancing, I had to push her around and uh...she'd say "don't push me so much"....And um, we stopped going places. We gradually she don't want to go here, she don't want to go there. [so] I'd just say "okay, if you don't want to go that's fine". But then I could go for my walk, you see. I'd leave her home so I just go for a nice walk all around here and we use to go for walks and walks around here for miles...and we had bikes, we used to go for bike rides all around here. We'd go up these side roads... But the last two years, the bikes haven't been out, probably the tires are no good now.

He concludes that "we were very active" and "it slowed us down tremendously, tremendously". It is this `slowing down' and increasing isolation, as opposed to either his wife's actual symptoms or the additional work associated with her deterioration that seem to have been the most difficult part of the experience for Mr. Malloy.

In keeping with his efforts to relegate his wife's functioning to the background, Mr. Malloy's increasing assumption of responsibility for household tasks is not consistently positioned as a response to his wife's illness. Rather, although Mr. Malloy acknowledged that over the past few years he had assumed all responsibility for managing the home, the assumption of these tasks was often placed within the context of his own retirement and not his wife's illness.

> I took everything on. Yeah, I've been doing everything for the last two and a half, three years. I didn't mind. I'm retired, I mean.. What! I've got all the time in the world.

Asked specifically whether he began taking on more and more responsibility as a result of his wife's deterioration, he responds:

> Yeah, probably, I guess. I never thought of it that way. But I'm retired, and I had a lot of time on my hands, so I'd do a little bit of work and I guess it just gradually kept going and I kept - probably babying her a little bit, you know, doing a little bit more for her. And then I noticed that she could..that she couldn't um make the tea properly, you know, it was as simple as that, start noticing things like that and drying the dishes and gradually it got that I was doing the whole thing and then if she came

down, came downstairs, and say "oh, I can do that for you" I say "okay" and give her the towel and...she'd just do about one and say "well, I can't do this". Fine. Then don't bother me then.

Although he recognizes her decreasing capacity here, there is some question regarding whether he sees her deteriorating function as a precipitator or response to his increasing assumption of responsibility. Furthermore, he then proceeds to normalize his actions once again. For example assuming responsibility for meal preparations is described as "no great deal" because "I always used to make some sometimes, especially after I retired, you know" so I "just slid into the slot and then that was it" ; it was "never an issue at all". He then concludes

> My boy is the same way, he, he does...cooking sometimes you know. He looked after the kids...It's something we've done. Just *naturally*. [my emphasis]

Thus, Mr. Malloy's way of dealing with his wife's illness seems to be to contextualize the experience of living with a memory impaired spouse within the normal and expectable. However, confronted with the `hard evidence' of a problem, Mr. Malloy is unable to consistently avoid the recognition of his wife's illness. In other words, although Mr. Malloy is intellectually aware of his wife's condition, and the associated implications, in his day to day understanding of the situation, this awareness is submerged by his expectations of normality. He teeters inconsistently back and forth.

The impact of his wife's illness on his own sense of self surfaced repeatedly.

Specifically, a sense of impotence dominated much of his conversation. First, Mr. Malloy had marked difficulties understanding his wife's illness and how it had come about. He wonders if he is to blame.

> ...I sat down sometimes and thought, "now what did I do?" That I've done wrong. Have I upset her, what... did I cause it?... Am I the cause of it, am I the problem for it? When we built our house, was the work too hard for her? It wasn't too hard for me, obviously...But, she had the kids and uh, well, we only had the one to start with but, she had to make the supper and bring it up and things like that, even though I was working from dawn until dusk building after working, but she um... did I push her too hard? She was just a young girl - well, I was just a young man too but...She was sheltered all her life, and suddenly she was out in the country, her folks aren't here, my folks were dead - I had brothers and sisters but it's not same. And here we are struggling along, trying to build a house and get more. And she had to use a scrubbing board...we had no water.. we had no electricity. We, I hauled the water everyday when I came home from a block away, in a ten gallon milk pail. So, it's... what did I do wrong?

He notes that he would not have these same kind of questions were his wife physically ill with something like cancer or arthritis "because cancer is a disease everybody knows about."

> well, dementia is gradually getting that way but it's not really. And it has to do with the brain which is totally protected with a big bone... so what caused it? We don't know the function of the brain, nobody can know how it operates...What is it, I don't

know. But I have often sat down and tried to think of something. And I'm not an educated man, so what the hell am I going to do? But I do feel guilty. That, that's the sad part of it.

In other words, the uncertainty associated with the condition translated, for Mr. Malloy, into the uneasy perception that perhaps he was somehow at fault. The implication seemed to be that he `should' be able to do something to make the situation better.

Similarly, Mr. Malloy clearly saw himself as "taking on" the situation. There is an expectation that he can `rationally' handle the situation.

From there on [after 1990] it was just let things go and pick up the loose ends. Just figure your way through it and try not to loose your cool. That's about the size of it. And that was that. Get upset? I'd just say okay to hell with it.

When asked about specifics however, he provided a markedly different description. Here he talks about his morning routine with his wife.

Well, any day really sometimes she'll get up and she'll have breakfast, like the first thing I do is get up and set the table and get breakfast going and usually just cereal, I have my porridge and she just eats cereal and toast. And then..some days, she'd get up, some days she wouldn't, and that's..."come on, get out of bed!" and then she'd come down and lie down on the couch or whatever. I said "you're not doing yourself any good that way, you've got to get walking and get some exercise". And gradually it got worse and worse and worse. Then she wouldn't eat her breakfast, then she wouldn't take her pills, then she wouldn't... and it just built up and built up

and then you just have to blow your stack and then I'd blow my stack and I'm alright.

It appears that Mr. Malloy had one set of expectations which were not entirely congruent with his lived experience. At an intellectual level he could identify the futility of arguing or attempting to reason with his wife. He set guidelines for himself to just walk away. However, translating these rational beliefs into practice seems to have posed some difficulties. What `got to him' was

> just her refusal of not doing things, and the irritating mannerisms of her, I don't really know..but that's about the size of it, the repetitiveness of her refusing to do things... and yet for her benefit she knew she had to do it but she wouldn't do it.

Mr. Malloy was left with was the perception that he was required to take charge and considerable anger at his wife because she would not let him. In other words, what `got to him' was the expectation that he `should' be directing the situation and the practical reality that he could not. He alternated between feeling "frustrated", "impotent", "negligent" and like a "failure" and feeling angry at his wife whom he blamed for his lack of control - she would not listen to him. At times, he could recognize that she was not capable.

> She was the dominant factor causing it [the stressful situation] but it wasn't her doing it, it was the lack of the ability to understand...I think. You had to cope with her misunderstanding and your...definition of what was right - and it had to be right because if she wasn't eating, she has to eat, so you have to domineer, but it was just the fact that I was trying to domineer but I wasn't' trying to domineer.

However, he continued to see her as having some ability to control her own actions despite his intellectual recognition of her dementia.

> And then when she forgot herself and I had to clean her up, you know, she'd never stand still when I was trying to do it and that upset me and uh...she'd say "you know I can't help it". I said "you **can** help it, you **can** control it." (emphasis his)

Unable to consistently view her behaviour as a symptom of a disease, then, Mr. Malloy is angered by his wife's apparent refusal to listen to him. Her behaviour is seen as "taunting", a blatant lack of regard for him. He summarizes the process as:

> it's like ...having a bad job probably or having a job and then somebody at work keeps bugging and bugging and bugging and finally you just loose your lid and bingo. There's no animosity between you. It's just that they would just bug you. And you told her to stop it and she won't stop it and then you go and.. flip out.

The link then between his wife's behaviour and the dementia is paradoxical. His wife's behaviour is seen as a separate entity , an aggravation in an already problematic situation rather than as an integral part of the problem. In essence then, Mr. Malloy may be dealing with two distinct problems.

As long as he could get away, "go for a walk, hop in the car and go for a drive...anything", he could manage. These outings seemed to provide him with the space to pull himself together. This was how he and his wife had traditionally handled arguments.

> We were always a couple that, if one got upset at the other, we'd just leave it be and walk away. When it got real bad, yeah, we just try to get away from each other and, just for a little while, you know, and then we'd come back with smoother waters,

calm down and then we can swim them again, you know.

This coping mechanism became increasingly unavailable to him as his wife deteriorated. The more confined he became, the more frustrated by his inability to control his wife's behaviour. The battle for control eventually cumulated in the following episode and precipitated admission to a nursing home. To me, this episode captured the mixture of frustration, bewilderment and self-righteousness that pervaded much of Mr. Malloy's general story.

> But on that Monday two weeks ago, last Monday, um... I said "come on, get up" .. "yeah, okay"... So I come down .. and uh after awhile I thought well, I better go see again. I said "are you going to get up?" "Yeah". So I come back down, I put my porridge in the microwave and I sat down and I ate my porridge .. went back up and she's still in bed.[voice becoming increasingly forceful] I says "come on, get up! You've got to go to [the day program] today". She said "I'm not going". I said "oh, yes you are, you missed last week". And she says "no I'm not". And I said "oh, yes you are". So I came down and I had a piece of toast. I went back up, I said "come on now, up. And I mean up!" She said "no" so I just pulled the covers off. I said "GET UP!" and um .. she wasn't going to get up so I said "you've got to go to the bathroom anyway, you haven't been to the bathroom all night", so I pulled her up and pushed her into the bathroom. She walked out not going in the bathroom. I said "you've got to go in there and sit down." "I don't have to". I said "yes you do"... So she went in, and I came back down here [to the kitchen] .. and um ... had some of my

tea and went back up and I said "come on!" - she's laying in bed again. I said "GET UP". She said "I don't have to and I'm not going". That's the most she said for a long time. [laughs]) I says "all right". And I grabbed her and pulled her out. She slapped me, she gave me a wicked one. I says "that's it". I says "come on" and she was back down on the bed and she starts kicking and I grabbed her feet, I said "don't fight it" .. I said "you're out maneuvered so don't fight it" - or words to that effect with a few curse words in between. And she says "I'm not going". And I tried to get her nightie off and .. she whacked me again, so I grabbed hold of her hand and I said "one more and I'll throw you out the window." "Yeah?" I said "yeah!" So I held one hand down and I fought the other one off and I got the .. the um nightie undone, it was buttoned up here. She says you, "no, no, I'm not going". I said "if I have to tear that nightie off you, you're going". "Humh". So with that I let go of that hand and took this hand and ripped it off. I went [makes a tearing noise].... Totally out of control. Not out of control but just .. anyway, then I had to fight to get her to take her sleeves out, I said "do you want them torn off too?" So she let me take them off, then I get her half dressed and I said now go sit in the bathroom. She went to the bathroom and she just fiddled around there, then she came out, I said "did you wash?" "No". So I poured the water and gave her the soap and towel and everything the way I always do. I said "now wash your hands and face, or do you want me to do it" . Because when I wash her face I rub hard - well, I rub my own hard, so it's the same thing. So she played around, she fiddled and she fooled at this and that and she was just killing time. **She didn't know what she was doing, I'm aware of this. But here you've**

got the needle in and instead of pulling it out, you're just grubbing around and screwing around, you know what I mean, you know, and it's hurting. So, I .. got her uh .. and I said "well I don't give a damn if you wash or not, get in here". So I took her back in the bedroom, and I tried to put her clothes on. I said "okay, here's another one, put this one on". "I'm not putting it on" and she walked downstairs, went over there [points to sofa] to lay down. I said "you've got to come in here and take your orange juice and pills and your have some breakfast". "I'm not having anything". I said "fine, you're still going".... So, she laid there .. just a brassiere on, and I had to fight with her to get the brassiere on. She said "I don't wear that". I said "you'll wear one, you've worn one of these for 60-odd years". She said "no". I got it on and then she came right down stairs here and I threw the blouse on the bed and I said "okay, do it yourself but you'll look funny at the day care with no blouse on".

Deb: Did that affect her at all?

Dave: There's nothing there.

Deb: So that wasn't affecting her but it was important to you that she looked good?

Dave: Oh yeah, well, what do you expect?... And uh, finally, I walked upstairs, I got the blouse, and I came back down and I brought her shoes down, and then, she let me put her blouse on and then she laid down and put her feet up again. Course you see she's got to pull her knees up to get on there, and I said "okay, let's... sit up, and I'm going to put your shoes on". "No". I said "I'm going to put your shoes on". She said "no, you're not". So I grabbed the one arm and I drew her up so she's sitting up straight and I tried to get her shoe on and she flopped down again. I said "okay,

if you want to do it that way, you'll do it the hard way" so I grabbed one ankle and I picked it up and I forced the one shoe on, and I knocked that out of the way and I got the other one on and uh .. the carpet's quite soft to walk on, it's got a good padding underneath so,... she's got her feet back up on there and I said "come on now .. UP". "No, I'm not going". So I just got one arm, one leg and pulled her and dropped her on the carpet - Do you blame me for being agitated? So I says "okay, that's it". Usually I get the dishes done, but I didn't, I said "that's it, we've got to go, it's time to go". So, I got her, and it was cold that day, so I got her winter coat out, a nice down coat, and I got it on her, and then I had to get my shoes and what not on. So by the time I got that on she was laying down again. I said "come on". She says "I'm not going". I said "you're going if I have to carry you there". "Humph". I said "you just `humph'ed once to often". So I pulled her up, threw her, got her over my shoulder and got to the front door, and was starting to pull the front door open and then something hit me and I said "what in Christ's name am I doing this for". So I put her on her feet and I said "go lay down, I don't give a damn what you do". That's when I got on the phone [to the nursing home].

The frustration and the sense of impotence are clear. Additionally, there is a seeming legitimation of his anger. Placement in a nursing home was seen as the only choice he has.

But that's the point of no return as far as I was concerned, because I don't want to take any chance, I don't want to hurt her.

I would like to have her here all the time. I don't mind doing the work and helping

her out and doing things. If she could just turn around and do what she's asked. I'm not telling her to do it, I'm asking her to do it...[If I could have gotten some] cooperation ..there would be no problem...Cooperation there and **nobody here would have known that she had Alzheimer's.** [emphasis mine]

This decision is positioned as "the hardest decision I made in my life".

....I said no way she's going in a home, over my dead body. but then I realized as I told you before that it might be her dead body, not mine.

Moreover, despite his recognition that the situation was explosive, Mr. Malloy reported an ongoing sense of guilt about having his wife admitted to a long term care facility. He feels like a "failure"; he did not live up to his part of the `bargain'.

She had looked after me, she had given me nice children and made a nice home, now it's my turn and that's what it was, and our marriage vows said until death do us part, why should I put her in a home.

He talked repeatedly about bringing her home. Interestingly, although he acknowledged his wife's lack of co-operation as the precipitating his own loss of control and subsequent placement, often this aspect of this situation is downplayed. He recognizes that:

I don't know, I'd like to have her back but I know what it would be like when I got back, it would just be back to the same old thing again.

However, throughout both interviews he repeatedly delimits his control over this

decision. Instead, he positions himself as balancing his yearnings to take his wife home against the expressed wishes of others with more objectivity and expertise. For example, he is following the advice of his physician.

> I still have guilt. I guess that'll always be with me...But uh, I spoke to [my doctor] and my blood pressure's up again....and the doctor say, I told him, I said " I almost took her out" . He said "Don't do that" He said, "that's a backwards step." I said "well, is it?" I mean is it? He said "well you say it's pretty well cleaned up now [referencing previous concerns about his wife's treatment at the nursing home]?" I said "yeah, it is". And he said "well, it would be a backwards step so don't do it".

Similarly, his children are credited with considerable influence; "I would take my wife home tomorrow but my kids would hide me, they'd skin me alive". It seems that Mr. Malloy maintains a fine balance between his sense of control in the situation and his ability to turn to others to be `taken care' of.

In summary then, `reconstructing' Mr. Malloy's experience of living with a memory impaired partner raises several critical issues. First, his story highlights the struggle to maintain a sense of normality. This is done by positioning his wife's illness in the margins rather than seeing it as a centre, or `forefront' issue. To some extent, this allows Mr. Malloy to hold his wife accountable for her actions even when he is intellectually aware that she is no longer capable. It however also fosters a situation of frustration and impotence which circles, rather than names, the issues. Second, a primary issue in Mr. Malloy's experience is his increasing isolation and confinement; the inability to `get away' and to pursue his own interests. This need is clearly recognized by Mr. Malloy and is validated by his family.

Third, Mr. Malloy's sense of control in the situation is being repeatedly maligned.

The Meaning Associated with Service Use

Following a lengthy process of persuasion by the family, Mr. Malloy finally initiated formal support services approximately a year prior to Mrs. Malloy's institutionalization. In talking about the difficulty he had in accepting formal assistance Mr. Malloy reveals the multiplicity of meanings that he associated with service use. His story exposes diverse levels for making meaning.

Mr. Malloy's initial `automatic' response to considering the use of services was resistance to the idea. He identifies at least two meanings associated with this response. First, service use was equated with placement. In response to a query about his reluctance to utilize services, Mr. Malloy spontaneously volunteers that "I didn't want to see my wife go away". This is the suggestion he `heard' when his children began to talk about utilizing formal supports. In other words, although the stated objective of formal support services is to enable the caregiver to retain their partner at home Mr. Malloy clearly had a different interpretation. Later the link is clarified; services are seen as the "last stop" before placement. For example, explaining the use of the day program to his wife, Mr. Malloy indicates that:

> I said "you've got to go [to the daycare]. If you don't you're finally going to end up staying there [at the facility]" I said "you won't like staying there, it will be all the time" I said" "But it's the last stop for me." And it was the last stop.

Second, the use of services was perceived as a threat to his independence.

> I think it's the fact that..I've..call it pride if you want. I've worked...always worked, always managed to get by and I guess we just say "well, we'll work it out, we can get by. We don't need help. We don't need a social hand."

Like Mrs. Cook, Mr. Malloy saw the need for services as somehow reflecting a personal deficiency. Interestingly however, Mrs. Cook's response was particular to her situation with her husband while Mr. Malloy's statement reflects a more generalized belief in the importance of self-sufficiency per se. Moreover, where Mrs. Cook could rely only upon herself, Mr. Malloy shares responsibility for `getting by' with a `we', presumably his wife. He conveys the impression that he is not alone.

The immediate connotations associated with the use of services then were negative; there was an immediate connection to dependency and institutionalization. Mr. Malloy however then proceeded to challenge this view. For example, he counters the perception of service use as an indicator of dependency with the recognition that his wife should never have to suffer because he has "paid his dues".

> But on the other hand, I always maintained that my wife would never, never starve, nor my kids, I said even if I had to pick up a rifle and rob a bank, it just wouldn't happen. After fighting four and a half years over there I'm damned if I'd let my family starve, go hungry and that's that's my nature.

Thus, although "pride" made it difficult to accept assistance, Mr. Malloy can debate this pejorative connotation by claiming a sense of entitlement based on expectations of reciprocity. Service use is reframed as something to which he has earned a right. Moreover,

it is repositioned as a necessary challenge he must assume in order to provide for his wife. Referencing his responsibility for insuring his wife's care Mr. Malloy asserts, "I can do anything for it". In other words, Mr. Malloy articulates here the process of reformulating service use from a symptom of personal deficiency to a manifestation of personal strength. He is using services for his wife, not for himself, and he has a right to these services based on his military record.

Mr. Malloy ultimately utilized number of different formal support services. For example, he had a homemaker coming in twice per week, was being visited by a mental health worker periodically, and had his wife enrolled in two different day programs each week. Additionally, he relied extensively upon both his own and his wife's physician, and attended several sessions of a caregiver support groups.

On a practical level, services attained some status as "a relief". They allowed Mr. Malloy the opportunity to pursue his need for physical activity such as swimming and walking. The degree of relief was limited however; "it was helpful but uh..in the back of your mind you're still, you've still got it, your still..over there." Moreover, the impact was not entirely positive. For example, the stress associated with his primary support, the day program, was clear. He describes the process of getting his wife ready each day for the day program as "maddening" and "upsetting".

> I had a heck of a time getting her to go to the day care the first time...I really had to convince her. Then I had to fight with her to go to the day care after that....And she used to say "I don't want to go back there, I don't want to". and I'd say "you've got to go back there" and try to force her into it. And I said "if you don't go back" I

said...."the way things are going you're going to have to go in a Home". But I didn't use that too often because it upset her.

It was during this struggle to get his wife ready for the day program that Mr. Malloy finally becomes convinced that the situation is beyond his control. The `last step', placement, was taken. The day program then provided relief but was also a source of stress and a visible reminder of his wife's deterioration.

The value of other services is less clear. Mr. Malloy queried the benefit of the homesupport services and was particularly skeptical when services were directed toward assisting him with the caregiving tasks.

My daughter in law, she kept saying "dad, there's a problem, you can get all the help you want". I said "I'm not worried about help" I said "I don't mind doing these things." You know, what I find now, I... this morning, I got up and I made my supper, it'll last me for three days, and I done the floors, I done all the dusting, everything off there - uh the [Royal Dalton] statues of Eunice's...And I still got lots of time. At 10:00 I usually make my bed, clean up there. At 10:00 I was finished. So why do I need somebody in here to help me do that?

In fact, Mr. Malloy derived considerable pride in his ability to manage the homemaking tasks and repeatedly asserted that he did not mind this work at all.

...doing everything around the house I mean that sort of, that wasn't anything, that's doesn't bother me. There's no problem. I don't mind doing things like that. I always had to fend for myself anyways pretty well.

I saw this as one area where he felt competent and in control. Within this context, service use was seen as, at best, useless:

> So, [the homemaker] started to come, but she came down primarily to do the housework. [Begins to laugh - then explains his laughter] Well, she used to come in and she says "what can I do for you?" Well...I don't know. Everything's done. Because I got up in the morning and uh..have breakfast and start cleaning things up and I'm finished by 9:00, 10:00 am. - everything's done.

and, at worse, creating more work for Mr. Malloy.

> She used to come in and she'd [say] uh..well, "leave the washing for me" but I don't like people washing my personal things...So I used to wash in the morning and then uh, as soon as I got downstairs in goes the wash on Thursdays. I don't, I used to do it Mondays and then I changed to Thursdays to coincide with her so she'd have something to do.... Uh...they were willing to do everything, but there was nothing to do. And I couldn't see letting things go just to have somebody do it for me. [As a result you're] ...thinking of how, what can you do to help them? They're helping you so how can you help them. So really, it was a case of helping help - if I can put it that way.

In other words, although practically there were some advantages to utilizing services, there were also disadvantages. Like the day program, home support services served the function of providing some respite. However, they also interfered with Mr. Malloy's daily routine, interrupted a source of satisfaction in his life, and added extra work. Using the day program created a stress and forced a confrontation with his wife. For each `support' service there

were associated oppositions.

Despite this, services were clearly seen as responding to Mr. Malloy's needs and not his wife's. For example, although at one point he does suggest that attending the day program was "a break for both of us - and it did work both ways", he also acknowledges that his wife "didn't want services" and recognizes her response to the programs as generally negative. Ultimately, he discounts her response; "they don't have the facilities to realize they are being helped". He also definitely questions that his wife even benefits from services; in one program Mr. Malloy indicates that "she'd go to sleep most of the time" while in the other program "I think she enjoyed it when she was there. I don't really know, I didn't hang around too long".

There is some hint that positioning services as responsive to Mrs. Malloy's needs may have been problematic for Mr. Malloy. He spontaneously volunteers that one of the major problems with services is that the homesupport workers are "too good to his wife". Specifically, he critiques their support based on his perception that they precipitate a negative evaluation of his own work.

> I'd been building up to it, and building up and building up and refusal, you see, what makes it all so bad is that these girls from the [homemaking agency] do a beautiful job, they're excellent. And I hate to say anything, but I'm not saying it against them, I'm saying it against the system which has to be this way.

He goes on to provide an example which contrasts his difficulties in getting his wife to take her pills with the ease that the home support workers accomplish this same action.

> [The homemaker] no problem. I fight like hell with her to try to get her to take them.

[It makes me feel like] sending her to the moon.

He recognizes that their positive response may be related to their gentler handling of the situation but suggests the problem with "the system" is "because they were too good for her. Then she expected it from me".

See they only have her for, they only have her for three hours so they can afford to do all this, right. I had her for thirty six hours, and her demands...they want it now.

Rather than being appreciative of the positive way that his wife was handled, Mr. Malloy felt that the home support workers established expectations that made his position harder for him. He discounted the benefits to his wife and focused instead on the threats to his own perception of competence.

On a practical level then, meaning was assigned to service use based upon Mr. Malloy's personal needs. Service use provides a break - "Well, I wasn't getting out" - but it also threatens his sense of competence. Importantly, he views services in relation to his own needs. He retains some sense of himself as an independent, autonomous individual with a right to a life of his own. An expectation of self sacrifice, although present at times, was not as consistent as it was for example, with Mrs. Cook. Rather, Mr. Malloy was able to define support services in relation to his own needs and is then able to utilize them, despite his wife's objections, in order to address these needs.

This sense of entitlement was different from Mrs. Ford's and clearly lacking in Mrs. Cook's story. I identified two aspects of his experience which seemed to 'engender' positive connotations around the personal use of services: the creation of boundaries and the presence of external validation and support.

Boundaries were created in two ways. First, Mr. Malloy distinguished between his `self' (the subject) and his `temper' (the object). The purpose of this split is to "produce the ability to control, manipulate and predict the behaviour of its objects" (Code, 1991 p. 139) in this case Mr. Malloy's `temper'. In other words, in creating this dichotomy between his `self' and his `temper' Mr. Malloy can distance himself from his emotional responses; he no longer `owns' the responses rather he is responsible for `controlling' them. I became aware of this when I listened to Mr. Malloy describe his decision to utilize services.

Mr. Malloy indicated that the use of services was initially raised by his children. His response to their suggestion was that " I can cope, I don't need anyone...And I could cope". Interestingly, he then proceeded to identify several incidents where "I flew off my handle".

> I just, she kept on, like being on at me, little things you know, just kept going repetitively, the same thing. And it got worse and worse and worse and I'd go up to, I play organ a little bit and she'd come up and taunt me at the organ or go do something else. She'd taunt me when I was doing it to get attention, that's primarily what it was, she wanted attention. And it just got so bad that I had to phone somebody so I just phoned them. My daughter came up. And just last year, it got real bad and uh..I told my daughter "You'd better come up here quick", I said, "I'm reaching the end of my rope". I said "your mother's struck me and I'm going to strike her back if she's not careful, and if I do that she's going to go right through the wall"

Initially, his assertion that he could cope, coupled with his concrete examples suggesting that, in fact, he couldn't, seemed discrepant. Gradually however, a pattern

emerged which might account for this seeming contradiction. Specifically, Mr. Malloy appeared to differentiate between his `real' self and his actions. His actions were seen as outside of himself, a separate entity beyond his control.

> Well, I don't think it's my fault entirely, it's..it's my temperament. I have no control over it. But my brain is..independent.

> No, I don't think I've been pushed to my limit. Just my temper (laughs).

It's as though his temper is not connected to him. Rather, it is objectified as being outside of his self, an `it' for which he is not responsible.

This split seemed to have important implications for the use of services. Specifically, it allowed Mr. Malloy to acknowledge a need for help based on his loss of control while simultaneously preserving the facade that he is still in control. `It' is getting the best of him and therefore must be contained. Services then can work collaboratively with his `real' self in order to manage his temper. Moreover, this differentiation allows him to remain blameless in the decision to utilize services and then, later, to seek placement; his wife's admission to a nursing facility is "because I wanted to protect her against **me**" (emphasis mine) " I was going to lose **it** one of these days". He would "take her home tomorrow" if he could control "it". Mr. Malloy's problems are located in his "temper", and because this was not explicitly connected to the "I" his "I' was less threatened by his difficulties in coping. In fact, his `I' is stepping in and assuming control over `it'.

A second way that Mr. Malloy was able to create boundaries which legitimized the

use of services was in his understanding of his role as `caregiver'. Mr. Malloy situated his caring activities in his marital role; "Isn't that what marriage is all about?" he asked. His interpretation of being a caregiver however was that you "cared deeply". He generally seemed able to separate caring as physical labour from caring as an emotional state. By making this distinction, Mr. Malloy opened up the space to use services; it was not necessarily his role to provide instrumental care although it was his role to care.

This meant that unlike most of the women, there were clear boundaries related to what Mr. Malloy could reasonably be expected to do. For example, while relating a story about losing his wife in the public restroom of a large mall, Mr. Malloy tells of the instructions he gave his wife before entering - noting how she required simplified, step-by-step directions. He suggests that by doing this he has done all that he can because "I couldn't go in the public washrooms"; the mere suggestion seems so ludicrous to Mr. Malloy that he begins to laugh at the prospect. His wife subsequently wanders out while he is using the men's facilities, and gets lost. Mr. Malloy suggests that:

> I was at fault. I was negligent. It was my responsibility. But what could I do? I couldn't go in the bathroom with her"

In this statement, Mr. Malloy seems to be identifying the contradiction between his sense of responsibility and his recognition that there are limits to what can be expected of him.

Establishing boundaries regarding what could reasonably be expected had the advantage of providing the space for service use to be seen as legitimate. For example, Mr. Malloy initiated services in order to assist with his wife's bathing and felt quite comfortable delegating responsibility for feeding her to the nursing home staff. Since he did not believe

that he `should' be providing this assistance there was no inclination to perceive himself as somehow inadequate for accepting assistance. In other words, by framing the use of services as related to tasks outside of his domain, on at least one level the use of services could be perceived positively as offering a valid source of assistance. Mr. Malloy could then work more collaboratively with the service provider.

The second aspect which promoted Mr. Malloy's use of services was the external validation and support available to him from both his family and service providers. Specifically, in our Society, the role of male/husband generally includes the expectation of being `taken care of'. This seemed to play out in Mr. Malloy's story. He clearly receives the message that services `should' be directed toward preserving his own well-being even though his wife is not receptive to using them.

> This has always been her way - she's independent. And why do we want someone in here because all the housework's done, nothing to do...just sit around and read and go for walks and stuff like that, you know. But what we've really got to realize now, what really they [his family and the service providers] were saying is "*you've got to get out*". [emphasis his]

In particular, Mr. Malloy seemed to feel comfortable turning to his family, particularly his daughter and daughter-in-law, for support in a way that few of the women did. He identifies his children as the primary motivator of service use. Concerned about his well-being they seemed to validate his right to his own life. Furthermore, through their expression of concern, Mr. Malloy is provided with a language for fulfilling his own needs while attributing altruistic motives to his use of service; services are positioned as both a response

to Mr. Malloy's increasing confinement and as an attempt to placate his children.

> well, I wasn't getting away and the kids were getting on my back... I guess they could see the changes but I couldn't.

> It got worse as things went along and uh...when it got right down to the brass tacks, I got Mary [the homemaker] in to give her a bath. Then they kept saying well this was, "to keep her here" they said "you need more help. You've got to be able to go some place because you can't go any place in two hours or three hours".. and uh, I said "no that's quite alright". I used walk along here, go for a three hour walk, two hour walk, whatever. And um, they said "well, I think you need, you need a little help".

At times, the impression given was that he was `allowing' others to take care of him, to attend to his needs. Even a request for assistance is framed as though he is bestowing a favour.

> I said, "I've got to go for a two day break". They [his children] said "fine. Go!" I said "well, first of all, there's a catch". They said "what's the catch?" "Either one of you two have got to go up there the days I'm not there. Or one day each." So they worked it out.

Outlining his experiences with formal support service providers, Mr. Malloy conveys a similar impression. He is "convinced" to go to a veteran's dinner when the Social Worker who "gets this out of me somehow" - referencing his plan to cancel because he couldn't leave his wife - cajoles him with a plan.

"You will go if you know I can get somebody in?" I said "yeah, but it's gonna be a long time". I said "I've got to drive to the city, take the subway downtown..before supper have a little get-together and then supper and then...I said "this better be from 3:00 up until 10:00 at night".

When Mr. Malloy talked about the use of services his words belied his involvement in the decision making; services are being done to him. Yet he clearly was the `puppet master' - pulling the strings in the background. I wondered if paradoxically, this was his way of retaining power in the situation. Specifically, by `allowing' the use of services Mr. Malloy could assert that he "didn't mind" devoting his time/effort to his wife while simultaneously insuring that his own needs were addressed. Interestingly, his needs were being met largely by other women: his daughter, his daughter-in-law, the female Social Worker, the female placement co-ordinator, the female homemakers.... With all of these women attending so conscientiously to his needs, Mr. Malloy could deny that he was even obtaining help. In other words, perhaps because of his gender he could assume that someone would take care of his needs in a way that I suspect none of the women could.

In summary, Mr. Malloy's story reveals multiple layers of meanings associated with the use of formal services. At the most emotionally spontaneous level, service use is pejoratively associated with institutionalization and dependency. On a more `rational' level services are able to begin to address some of Mr. Malloy's personal needs such as his requirement for periodic respite. However, practical issues in carrying out this mandate are raised. Philosophically, a sense of entitlement to services is established based on Mr.

Malloy's positions as a male in a patriarchal society and on his ability to name his societal contributions as a war veteran.

Conclusion

Mr. Malloy's account begins to add dimension to the experience of living with a memory impaired partner. For me, it introduced three key points.

First, his story makes explicit the complexity associated with naming the experience. For example, Mr. Malloy demonstrates that a diagnosis of dementia, in and of itself, does not necessarily result in a redefinition of one's relational experience. Until the situation is reconceptualized as extraordinary the relational status quo can be preserved (at least to some extent).

Second, Mr. Malloy's story made visible the loss of competence and control associated with the experience of dealing with a memory-impaired partner. Mr. Malloy alternated between personalizing this loss of control and blaming his wife for the situation. Ultimately it was his inability to control the situation that resulted in his decision to have his wife institutionalized. This loss of control was perceived as a personal failure.

Finally, Mr. Malloy's story suggests the importance of gender for making meaning about service use in a way that promotes a less pejorative interpretation. Mr. Malloy has a language for naming his own needs and receives external validation and support from both family and service providers to respond to these needs. Neither the language of personal entitlement nor external validation and support for personal needs were identified in the stories of Mrs. Cook and Mrs. Ford.

CHAPTER 6

CARING: BECOMING A `NON-PERSON'

THE STORY OF GORDON ARCHER

Setting the Stage

Gordon Archer is a physically fit, dynamic 67 year old man. A journalist by profession, he presented as succinct and analytic with a self-described tendency to be "critical". He exuded an aura of competence and confidence.

He was referred to my study through the local home support service agency. He lives with his wife Penny, who suffers from Alzheimer's Disease. Interestingly, although Mr. Archer was utilizing a day program twice per week, and had both a private cleaning lady and a volunteer assisting him, two separate referrals to my study were initiated on his behalf. Later, while reading the overview of my study which indicated specific interest in talking to spouses who were not using support services, Mr. Archer volunteered spontaneously his opinion that this was probably the reason he had been identified as a suitable participant by the agency; he was their "hold out". In other words, although by objective standards Mr. Archer did not meet the criteria for inclusion in my study because he *was* using community support services, subjectively both he and the two community service providers with whom he had had contact saw him as an appropriate participant. I was interested in exploring this discrepancy.

When approached, Mr. Archer was quite receptive to participating and readily

scheduled an interview to take place during his wife's next visit to the day program; later, he jested with an underlying seriousness that he had relinquished his very limited, and valuable, free time in order to participate. He signed the consent form with no hesitations. However, he acknowledged some reservations about allowing himself to be taped and throughout the interview he remained conscious of the tape recorder; toward the end of the first interview he requested that I refrain from taping so that we could "just talk".

Two interviews, totalling approximately five hours, took place with Mr. Archer in his home. Because he wished to limit disruption, both of these interviews occurred during his wife's scheduled participation in a community day program. This meant that I never met Mrs. Archer. It also meant that the length of both interviews was dictated by the amount of time that Mrs. Archer spent at the day program. Specifically, interviews started as soon as Mr. Archer returned home from dropping off his wife and ended when it was time for him to leave to pick her back up. Throughout the interviews Mr. Archer maintained a careful watch on the time in order that he not exceed his allotted time.

Mr. Archer was verbally fluent and expressive. He dotted his narrative with stories about his previous life experiences seeming to use these stories to position himself as a "knower" with a history of accomplishments. He fostered this status in his relationship with me by subtly positioning me as student to his teaching. For example, he offered advice several times regarding the wording of my questions - contextualizing it with "I always told my students..." - and he downplayed my professional background and experience. He also comfortably assumed the status as the `expert informant' in the interview.

Mr. Archer appeared to derive some benefit from his participation in the study.

Although he fluctuated in his perception regarding the utility of describing his experience to me, throughout the interviews he asserted how good it was to talk because "I don't ever talk to anybody - I've got a wife that can't talk". At the conclusion of the second interview he notes that "I'm glad to have someone to talk to even though it is not on my favourite subject."

> The main thing about talking is to get a reaction. I don't get a reaction from Penny you see - I say something to her and she'll just sit and look at me and nine times out of ten she doesn't - I think sometimes she doesn't even hear me.

He asserts that "caregivers'" need someone to talk to.

Background

The following biographical information was provided by Mr. Archer as a context for describing and explaining himself.

Mr. Archer was raised in England during the War. He indicated that during the process of undergoing psychological testing for career direction, he was surprised to discover that his childhood was considered to have been quite tough by the psychologist. Except for the fact that the war was in progress and there were frequent food shortages, Mr. Archer could not imagine what had lead to this conclusion. He supposed that he didn't identify it as a particularly hard childhood because

> ... everybody has hard things, things that seem hard to other people, have hard things happen to them. You will have things that happen to you which I probably think are very tough and you think oh well, it's part of life.

As an adult, Mr. Archer "left a good job in Britain" to immigrate to Canada.

> I came because I wanted to come here, I thought it would give us a better life and um, I came from a very good job in Britain. So, that..puts me and others like me in a category which is slightly different from those who were refugees trying to escape. They used to argue - they don't do it so much any more I notice - that people who um, immigrate to Canada or anywhere, are people who've made a deliberate choice and are usually very independent, strong minded people....Um, well, when you do it you don't think that. It makes sense when people say it to you, as they were to me 25, 30 years ago. They say well, "Why would you give up a good job to come over here?" and we'd say "well"...and we find most people who come over here really do have something extra to give to the country.

A journalist by profession, Mr. Archer initially worked in a private corporation and then obtained a post-secondary teaching position. Throughout the interviews, he frequently referenced himself within his professional background. This included recalling interesting stories (some of which were slightly risque) about his experiences. He noted repeatedly the fulfilment he had obtained through his work, particularly as a teacher. Much of his sense of self seemed grounded in his career.

Mr. Archer provided little information regarding his relationship with his wife. He did note that his wife had been very independent and had owned her own business. "We had a very good relationship and we had, you know, mutual respect for each other's careers." A paternalistic tenderness seemed to characterize his current relationship with her.

Mr. Archer has two sons - he laughingly pointed out that he had "made the same

mistake twice" by having boys rather than daughters. This was related to his belief that daughters could be depended on to help while sons could not. Regarding his children he noted that

> he [youngest son] is very good with his mother, exceptionally so for a young guy but he's quite a bit younger than his brother. Um, my eldest son is very very successful in business, has three kids of his own and um, he's used to people doing what he tells them to do, so he doesn't like it when the old man comes along and tells him! [laughs]

Both sons lived within easy driving distance and regular contact was maintained with both. Mr. Archer identified them as his first line of support.

The Experience

At the onset of the interview, while making tea and putting groceries away, Mr. Archer interpreted the purpose of my study as "you want to know what it's like for caregivers'". He then summed up his experience as "this is it, you do everything". Since I had not made any reference to "caregiver" I found it instructive that Mr. Archer would assume this starting position.

After several minutes of informal chatting, the interview `formally' began when I asked Mr. Archer what it had been like for him since his wife had become ill. Mr. Archer started by giving a retrospective understanding of his wife's early symptoms; incidents that had once seemed isolated were now linked together as signs of an illness. He credited his

children with helping him to recognize that something was wrong and "we started making formal investigations". He goes on to briefly outline the difficulty in obtaining an Alzheimer' diagnosis then, spontaneously, switches the focus onto himself.

> ...it takes a while, really, in fact they never do really decide it's Alzheimer's. Um...so that's were we took it from there. And then I decided I wasn't going to be able to work any more so I, though I was reaching retirement age, I was suppose to carry on so I had to tell them I wasn't going to be able to do it. So I...just packed it in and spent full time looking after her, which I've been doing now...this is my second year.....I've been looking after her obviously since she started but I retired in '91? Yeah I guess, '91.

For Mr. Archer then, an early effect of his wife's illness is that it forced him into a retirement which he later acknowledges he did not want to take. The matter-of-fact manner in which he conveyed this information imputed a sense of inevitability in his `decision' to take on his wife's care "full time". In fact, throughout both interviews, Mr. Archer straddles the precarious position of expressing his "bitterness" about his "forced" retirement without implicating his wife in his rage. Specifically, he alternately directs considerable anger toward "ageism" and "stupid regulations" while simultaneously positioning his retirement as an obvious response to his wife's illness that is "not anybody's fault". As a result, although Mr. Archer initially presents his retirement as an active choice, this impression is contradicted repeatedly and it became increasingly unclear the extent that Mr. Archer felt he had any control in the decision to retire.

Mr. Archer seems to mark the beginning of his positioning as "caregiver" to when

he quit his job to look after his wife "full time". A dominant theme in his story revolves around the loss of status and power associated with this transition. For example, he talks about his feeling that since his retirement, he is aware of people "talking down" to him.

> ...and it's kind of hard for you to come from an executive position and suddenly realize people are starting to patronize you.

He notes that while working he was considered "capable" but "now I'm retired and suddenly I'm a non person." He feels he has been "discarded". In other words, Mr. Archer's assumption of the caregiving role in relation to his wife, takes place within a context of decreasing power where he feels discounted and unimportant. His new status as "caregiver" does not replace the status and power he held as a teacher.

This sense of powerlessness is exaggerated by the experience of living with a memory impaired wife. Mr. Archer was very vocal regarding the impact that assuming the caregiving role in relation to his wife had on him. Caregiving requires that "you gear everything around, out of necessity, not altogether out of choice, but out of necessity I gear everything around having to look after my wife". The result is that his life is "on hold". He is "existing not living". He is being "alzheimered to death" because "every conversation veers around Alzheimer's disease". "One tends to become a non person by virtue of your partner's, this illness". His needs are "secondary" and attending to them becomes problematic.

> One of the things you miss as a caregiver is your own independence. You um, you don't have any time of your own and even wanting to phone anybody, you can't very well because.. I don't like to stop my wife wandering around the house by saying stay

in that room while I go and make a phone call.

The hardship as far as I'm concerned, is getting free time to relax. And to go out occasionally, to feel free to go out. And that's the problem.

When asked if there was anything else he felt needed to be said, Mr. Archer responded:

they say with this illness you don't have one patient, you have two patients, or two sufferers, and I'm sure of that, I'm absolutely convinced of it. I know one thing, that unless you're doing it you can not fully comprehend what's involved.

...it's just, it's totally, totally foreign. I don't even know what it's like to lead a normal life anymore. I honestly don't. I can't remember.

Although at times Mr. Archer tentatively questioned the expectation of self sacrifice, in general he accepted this status quo based upon the premise that this was as it `should' be; his wife was ill and needed him.

I gave up the idea of considering working and... things have just progressed since then. So, what you have to become used to is the fact that you are watching someone slowly disintegrate before your eyes. They call it the living death, as you know, and actually it's the living death of two people really. It's not just for one because you're tied to each other irretrievably and unless you're quite callous - and

some people are - and quite prepared to say "well, to hell with it, I'm going to put her into a nursing home", you're stuck with it.

Mr. Archer matter-of-factly expressed the inevitability surrounding his assumption of the caretaking role with his wife. "Obviously" he has been looking after her since she first began demonstrating symptom. And unless he is "callous" - which would be demonstrated by placing his wife in a nursing home - "you're stuck with it". He later clarifies that:

> I don't feel obligated, but I just feel mentally that it's the only human, humane thing to do. She is my wife, she's a person I love very much and well, if that's the person you love the most, what would you do?

Mr. Archer does not perceive himself to have had any realistic alternatives. Using the language of love and connection his actions are grounded in the assumption that this is the only possible option open to him; to refuse this position would signify that something was wrong with him.

Practical implications arising out of his relationship furthered glued him to this position. First, Mr. Archer, like most of the participants in this study, identified himself as the most qualified person to look after his wife. Referencing his wife's inability to communicate he notes that:

> Unless you're with a person all the time, under these circumstances, you don't really recognize the signals. And um, you have to read people's minds, the sick person's mind. You have to develop a...it's a mental telepathy...which we have to a remarkable degree.

There is a `catch' to this.

> I have this terrible, I guess you could almost call it egotistical feeling that I can cope with her best. And that I don't trust other people to look after her.....And that's going to be my biggest problem and it is my biggest problem.....because by doing so **I'm making myself a prisoner.** [emphasis mine]

In this account, Mr. Archer explains both how he has come to accept the positioning of caregiver and how this position is maintained despite adverse implications for him. Specifically, because no one else has the same intimate knowledge of his wife, no one else can be expected to provide the same quality of care. If he seeks assistance with his wife's care then, it will be with the clear understanding that this alternate care will, at least initially, be inferior to his own. He will feel worried despite encouragement from others to attend to his own needs.

He also identifies the bind he is in with this account. Specifically, failure to seek help with his wife's care means assuming a sense of personal responsibility for creating his own problems. He is in a `no win' situation, caught between two conflicting ideologies. On the one hand, the unspoken assumptions that husbands care for their ill wives direct his course of action. This requires a selfless, other-directed focus. However, on the other hand, Mr. Archer is used to having his own personal power and being self-directed; he is a product of a culture that propagates autonomous, self-determinated behaviour in men. He expects himself to be able to maintain his own sense of self outside of the caregiving role. When he fails to do this he notes that "I think I've got myself into a rut". The implication seems clear - he is to blame if he can not manage to retain his independence and provide selfless care to his wife.

Mr. Archer identified other ways that I interpreted as enforcing the status quo. He cited several examples where self-directed pursuits had the potential to hurt his wife. For example, he felt that it upset his wife to see him reading because it reminded her of her own limitations. Similarly, Mr. Archer felt he could never become angry or blow off steam because his anger would "break my wife up, just demolish her". He would feel liable for harming his wife. He would also be responsible for calming her. He made clear the work involved in this. For example, he requested that the doctor speak directly to him and not his wife during her routine visits, because his questions "upset" her and it "takes me three days to settle her down again". Similarly, describing his morning he notes:

> When my wife got up, she was upset. I managed to talk her down finally, which is what you spend half your time doing, when you just talk and talk, anything, anything that works.

Fatigue played an important role in immobilizing Mr. Archer. He reported always feeling tired; exhausted by the reality that everything is on his shoulders. Thus, although he knew he `should' pursue his own needs because "I know I'm just, mentally I'm going down hill", the effort this would take was difficult to sustain.

In addition to the emotional and practical issues which pitted caring for his wife against caring for himself, financial issues surfaced which further complicated the experience. Specifically, the expense of alternative care surfaced. Like Mrs. Ford, Mr. Archer noted the tremendous financial responsibility incurred by the well partner. He was especially haunted by the "constant nagging concern" regarding the cost associated with

placement should it become required.

> They have to realize, and what this government in Ontario has to realize, is that there's a tremendous financial responsibility looming for caregivers. For instance, my wife is not yet 65, so she hasn't got the old age pension. Chances are she'll be in a nursing home before she's 65 at which point I will be presented with massive bills.....And this aspect of it is sort of at the back of your mind always - what if...when this happens how am I going to manage?
>
> Well, what I'm doing is I'm living as economically as possible and putting money away against the day when I have to pay for the nursing home...That doesn't leave for much of an existence.

Mr. Archer identified placement as a very real possibility. However, his perception of this possibility was ambiguous. At one point he identified it as the only thing that would "free" him and referenced placement as "inevitable"; in his account above, his "what if" is quickly replaced with "when". Alternately, he contextualized his inquiries into nursing homes as an "insurance policy" to protect his wife should his own health deteriorate or his wife become incontinent, and stressed his reluctance to seek admission. The placement decision seemed to encapsulate his quandary regarding his need/desire to function as his wife's caregiver versus his need/desire to have a life of his own. The two were clearly seen as mutually exclusive opponents.

The Meaning Associated with Service Use

Throughout the interview, Mr. Archer had two primary positions from which he referenced himself in relation to his wife; `husband' tended to characterize his previous relationship with his wife, while `caregiver' referenced his current position vis-a-vis the wife who wasn't "with us anymore". The move into this position was presented as a conscientious decision which flowed `naturally' out of his marital relationship but was concretized with his wife's diagnosis and his decision to leave work and look after her "full time". It did not replace his positioning as husband, but rather seemed to supplement it.

This dual positioning allowed Mr. Archer to situate himself both within the marital relationship and outside of it; he could interpret his caregiving activities as both an expression of love but also as `work'. For example, he could itemize the tasks that he was doing and identify the cost savings to the public because of his services while simultaneously asserting his commitment to his wife.

When Mr. Archer positioned his caregiving activities within a social context, he expressed strong feelings of entitlement to services. He queried expectations of total selflessness and objected to being treated as an "unpaid nurse". He denounced policy which stigmatized the families of mentally impaired relatives by providing public care to physically ill individuals while expecting families to cover the cost of care to memory impaired relatives. He identified the right to compensation for his caregiving actions.

> The doctors tell me she should probably be in a nursing home and I say, I'm not going to do it. If I'm prepared to keep her here, and they all admit that she's probably getting better care here than she would in a nursing home, I feel that the government

should try to pay something or contribute something toward it, in some way.

Within this context, he was able to legitimize his need for assistance.

I can continue the status quo forever. All I'm saying is please give me some sort of help to get, to free me up, to give me some free time. Like I don't have any social life. I'm not complaining - although I sound as though I am - I don't complain on a day to day basis but I'm conscious of it. Every time I move I have to think...okay....someone says "do you want to come to do so and so" I say "oh, that would be nice...- oh oh what can I do about Penny?" and immediately it springs into my mind so immediately I reject it - because I know I haven't got anyone to come and look after Penny. Or if I wanted to go um, out for a few hours, I'll have, as people have when they have children, babies, you finish up with a double charge, a charge for going to the place and a charge for having someone look after my wife.

From this position, Mr. Archer voiced anger and outrage at the treatment he felt he was receiving from the formal delivery system. He mocked the amount of care being provided as inadequate. Like Mrs. Ford, he saw it as a token.

... one reads so much about all this social...safety net that they talk about for help. And then you run into it and you find the net really doesn't exist and if it does, it's in a distorted form. I don't quite frankly know that there is one. I was talking to Nancy [the home support service co-ordinator] and she said because of Penny's illness she would be entitled to two hours a week from services and I said "well, quite frankly, two hours a week is no good at all".

Moreover, he strongly objected to the expectation that he pay for services. He felt this penalized him for requiring any time for himself rather than recognizing the services that he was providing; in essence, Mr. Archer identified the double message being given to caregivers regarding the legitimacy of having their own needs.

> ...there are lots of double standards used and lots of...what's the words, lots of rhetoric with regard to health care which I frankly find very difficult and most annoying. Unfortunately, one doesn't tend to do much about it - but I feel it.

In other words, by separating out his caregiving function and interpreting his actions within a broader, social context, Mr. Archer was able to justify his needs and claim entitlement to assistance. He could name the practices and policies that subtly sabotaged this interpretation.

This was not a safe position and I was uncertain the degree of comfort that Mr. Archer had in this location. First, frequently while raising questions about the entitlement of caregiver's to services, he switched positions from the subjective "I" position to the more neutral "they".

> one of the things that keeps coming up among the people who are in this type of situation is they're very angry at the government for trying to arrange long term care in people's home.....

> and a lot of people are resenting that because they feel that the government is abdicating its responsibility.

In this way, he seemed to distance himself from these expressed opinions.

Second, commonly after making a critical statement Mr. Archer seemed to follow

quickly with either a disclaimer or a modifier. For example, although he strongly stated his belief that assistance should be provided free of cost to caregivers when this is repeated to him he responded that "I am only suggesting that it should be considered". Similarly, although he repeatedly identified the "principle" behind the cost of services as accountable for his decision not to use services, when an attempt is made to pinpoint this stance he contradicted this statement and attributed his decision to refuse services to affordability; later, he returns, once again, to the `principle' point.

Third, throughout both interviews he repeatedly neutralized his criticism toward services by personalizing his reaction. For example he cautioned that his remarks were "highly subjective" and noted that "you've got to take this type of comment (referencing his negative experience with the medical profession) from perspective and not generalize from it". He contextualized his negative statements by suggesting that "I shouldn't be saying this" and after critiquing available services hastened to relay his knowledge of people who had found home support services useful. His own experience as a basis for formulating opinion was minimized as not sufficiently inclusive. Additionally, personal attributes were identified which discounted the generalizability of his perceptions; for example, he recognized his "unusual" need to be in control and highlighted his critical temperament. The net effect was to neutralize his `anger' statements by attributing them to an individualized reaction.

I was puzzled by the fluctuation in the tone and commitment to his message; while at times he sounded like Mrs. Ford, strong and decisive, she did not express the neutralizing that Mr. Archer did. When I attempted to `sort out' the messages I was receiving with Mr.

Archer, he acknowledged that *he* could not clearly define his position; he was "sitting on the fence".

I interpreted this in the following way. As a result of his status in the public sector, Mr. Archer was accustomed to having his work recognized and valued. This experience provided the context for constructing and interpreting his current work as caregiver. This meant that on the one hand, he maintained the expectations that this work would be valued and recognized. Anger resulted when he realized that this was not happening. However, on the other hand, the ideology of family care exerted considerable strength. Within this context, the caregiving role is constructed as a `natural' indicator of caring. Mr. Archer might recognize the work that he was doing, but he could not question that he `should' be doing it. The result is a tension between ascertaining one's rights and visibility as a socially recognized person, and remaining private and hidden. Furthermore, because family values were clearly accorded dominant status, Mr. Archer had to see his caregiving position `against the grain' in order to retain his anger. This viewing could be difficult to sustain particularly given the isolation that Mr. Archer, like almost all of the other participants, identified as an inherent component of the experience.

Mr. Archer makes explicit his unquestioned belief in the primacy of family care. As noted earlier, he positions himself as the "obvious" choice for taking care of his wife. "What are you going to do" when you "love" someone, he asks. He further clarifies his assumptions about family responsibility.

> The only real help you can get, I'm now convinced of it, is to have a large family....The other thing one has to have, I've noticed - it's too late for me now - is

to have a daughter. [laughs] But, I've often wished to have a daughter because I've watched people who were in similar situations and a daughter is always, almost without exception, they were there.

This statement is followed by a story about a neighbour whose daughter has moved in to assist her father in caring for his disabled wife.

The message I heard is that daughters are idealized as the only real source of help available to husbands. Sons are less dependable. Although he related a number of incidents where he turned to his two sons for both concrete assistance and moral support, Mr. Archer conspicuously restricted his expectations of his sons.

It's particularly unfortunate if you don't have daughters because son's are not as helpful and daughters-in-law are not as interested

At times there was a hint of anger associated with this limitation but more often he seemed to unquestioningly accept this state. For example, in reference to his expectations of his youngest son he summarizes the situation:

he's got a new wife and home to look after, and his wife is quite possessive, as most new couples are, you know and they want time together. So I don't expect too much from him, whereas a daughter would tend to make the time".

This assumption regarding the primacy of family care implicated formal support as "artificial" and hence, `unnatural'. Hopes that it could be otherwise are dashed by routines and schedules which maintain the distinction. For example, Mr. Archer describes his disillusionment in the relationship with a volunteer who visits his wife weekly.

When you set up an artificial situation one should really expect it to be artificial you

know...I was hoping it would develop into more of a casual friendship where she would think about coming around occasionally - I've said on many occasions "if you feel like coming around, or just want to check to make sure everything is alright, check her out a little bit, um you know you're welcome any time, evening or day time". But if she comes it's always by fixed appointment.

The disappointment was clear. Although Mr. Archer described the volunteer as a kind and very helpful person the boundaries surrounding the relationship maintained a distance that could not be overcome. This experience illustrated and fostered the divisive dichotomy between formal support and family support. Family support was natural and acceptable, formal support was artificial and inferior.

Although many of Mr. Archer's actions and responses were grounded in his understanding of his family obligations, another theme which dominated his experience regarded his perception of himself as an independent, autonomous person. Repeatedly throughout the interviews, Mr. Archer references with pride his independence and his desire to be "in control".

In many ways, the experience of living with a memory impaired wife fosters the illusion of a self-contained, autonomous self. Through the process of his wife's illness, Mr. Archer loses his closest relationship. His sense of aloneness surfaced quite poignantly when he began the second interview by relating a recent dream.

In fact, I had a dream the other night. I was kind of joking about it afterwards. I dreamt I had a wonderful conversation with my wife - of all things - and I realized later, it's because I miss the conversation with her so much...That's a funny thing to

dream. I woke up I said "well I just had a lovely conversation with you" (laughs) And of course she can't complete a sentence now you see. So it's very hard. [voice fades]

He described the loss of his wife's companionship as "the loss of my best friend". Other people do not fill the vacancy.

You finish up not having any friends because they seem almost nervous about having you around or your wife - not all the people but most of them I find.

Ultimately, Mr. Archer recognized that he will have only himself to depend upon.

...like I said to someone the other day, I can see what's around the corner, I started out with two dogs and a wife, and I'll finish up with myself, all by myself, in the house alone. It's going to happen.

Increasing isolation and disconnection then, are identified as a significant part of his experience. Mr. Archer seemed to be left with the feeling that he had only himself to depend upon. As he notes "I'm it."

I said to someone and he laughed the other day - I said "I wish just once when I woke up in the morning someone would bring me a cup of tea instead of my having to get up and made the cup of tea for the both".....It's that knowledge that you are the only one who is going to do something...nothing 's going to happen until you make it happen.

Although the situation becomes a reminder of Mr. Archer's aloneness, paradoxically it simultaneously attacks his image of himself as an independent autonomous individual

capable of controlling his destination. When talking about dealing with his wife's Alzheimer's Disease, like many of the men, Mr. Archer used metaphors and imagery reminiscent of a battle or competition - he "tracked" doctors and "hunted" down potential treatments. Through this process, the Alzheimer's Disease seemed to obtain the status of an opponent; it is perceived as a distinct, adversarial entity.

This stance has the advantage of depersonalizing his wife's symptoms. Mr. Archer was able to distance himself from his wife's symptoms.

> I think that what has happened is I've preconditioned myself so much I've absorbed myself in this illness to the point that I'm almost obsessive, and I've pretty well - obviously I don't know everything that's around the corner, but I pretty well know everything around the corner. And so I just think "oh well, that's just another phase of the illness".....I step away from it, you know.

However this perspective also had the negative repercussion of situating Mr. Archer in a loosing battle. The Alzheimer's disease has him "beat"; it's "winning". He is left with a feeling of "helplessness" because he cannot "overcome" the disease. He interprets this sense of helplessness as "degrading".

> It's degrading for me - to be the object of sympathy from people who um..um...feel a little bit superior because they don't have the illness. At least one gets the feelings that they feel that way. See, it's hard to distinguish genuine sympathy from condescension.

In this context, service use was seen as further eroding his sense of an independent,

self-sufficient self. He perceived the use of services as "humiliating" and described the help seeking process as being forced to "go begging" and to "eat humble pie". A sense of shame is associated with the use of services. "You feel you have lost...your independence". This is a central core of his sense of self.

I'm independent, my own person, and I **hate** to be dependent on other people..

This means that when situated within the discursive practices of individualistic determinism, Mr. Archer can not use services from a position of strength. Rather, there is something wrong with him, he is deficient, should he require assistance. Using services is perceived as a clear sign that he is not in control, that he can't do it on his own. He is no longer "independent". A pejorative meaning is attached to needing assistance because it is seen as being dependent. He is no longer his `own person'.

This association sets the use of services up as a signifier of personal inadequacy. Mr. Archer resisted this positioning by refusing services. He asserted his independence as a "hold-out"; perceived as a "bit too independent" by community services providers who had to "justify their existence". Additionally, services are resisted until they can be framed in a less personally threatening manner. For example, the use of a day program could be sanctioned because it could be explained on the basis of his wife's needs. Specifically, Mr. Archer contradicts my description of the day program as "respite care" and notes that "I don't have any respite". Rather, the day program was made more acceptable to him by

the fact primarily it's something that's not for me but for her because it gives her some interest, focus on something, people who are in a similar condition and she's

just last week or the week before started to go three days a week because she comes away much more cheerful - not she didn't a few months back.

Interestingly, this rationale was not consistent throughout Mr. Archer's story. For example, several times during the interview, Mr. Archer did in fact acknowledge some benefit from his wife's participation in the day program and at another point during the interview he noted that his wife did not like attending the day program. This may suggest the tenuousness associated with reframing the use of services. It also highlights the complexity associated with understanding how the meaning of service use gets constructed.

Regarding his dominant understanding of service use as stigmatizing, Mr. Archer was acutely sensitive to practices which could be construed as demeaning. He imitated the "wimpish, patronizing" voices that he associated with many Social Worker and described one particular encounter.

> There's one woman that is at the centre and she drives me crazy - she isn't even involved with the Alzheimer's patients, but she's involved with a lot of old people a lot of the time. And she talks habitually in this high pitched voice, it's like she's talking to a little child. And I'm not a little child, and I may have retired but I've still got my brain you know....

The "certain attitude of mind" that develops among service providers (especially Social Workers) is attributed to ageist beliefs and practices. After acknowledging his age and retired status as at least partially responsible for his treatment as a `non person' Mr. Archer switches positions to speak of the general treatment of `old people' by service providers.

> You watch people. I'm quite horrified to be quite honest. You watch people when they deal with old people. uh...and bear in mind that people are living much much longer now and it's nothing to run across a whole group of 80 or even 90 year olds..and nearly everybody who deals with them talks down to them.

In developing his opinion about service providers Mr. Archer provided a number of specific examples he had encountered and the impact these had had on him. For example, he named the abandonment he felt when the physician treating his wife with a test drug permanently left the country without arranging follow-up. Similarly, he describes himself as "absolutely disgusted" by a service provider whose initial interpretation of eligibility criteria for a service was overly rigid.

> ...these are the sort of things you run up against all the time...Also, the talking across people as though they don't exist - I resent them talking across my wife as though she's a non person...This almost robs people of their dignity. I mean literally, as much as you possibly can.

Overall, the majority of Mr. Archer's remarks about service providers were negative and highlighted their inadequacy and patronizing attitudes. Moreover, he switched back and forth between the treatment he had received and the treatment his wife had received suggesting a difficulty in distinguishing between the two. However, when questioned specifically about his experiences he denies that the majority of service providers had been disrespectful.

> Oh no. I must say that the, the, um, the services in general are pretty good in their treatment of people.

Despite this summary positive experiences with service providers were held up as the exception rather than the rule. I was left feeling quite confused regarding how Mr. Archer's conceptualization of service providers actually compared with his individual experiences. What did seem to surface is that service providers were presumed to be disrespectful and infantalizing unless proven otherwise.

Some services had one more pejorative meaning associated with them. Specifically, there was a sense that at least in some cases services were seen as a `set-up'. By this I mean that although there was a promissory note associated with them, ultimately the reality was that the situation would not improve dramatically. Service use was then in the precarious position of offering hope while simultaneously reinforcing the futility of the situation. This was especially apparent when Mr. Archer talked about his experiences with the medical profession. For example, he identified the role of the medical profession and organizations such as the Alzheimer's Society as providing hope to Alzheimer patients and their families. Caught in a double bind he acknowledged the importance of this hope, but also expressed anger regarding the failure to deliver on promises of "break through" and viable treatment options. Similarly, he spoke with frustration of routine medical visits which revealed nothing new and only served to upset his wife.

Conclusion

In Mr. Archer's account of his experience he makes visible the conflicting stances between caregiver as a socially organized position and the ideology of man as an autonomous, independent being. He also highlights the struggle to move beyond an

assumption of family care as the only site for providing care to a position where his work can be recognized and his own needs legitimated. The net result of these differing positions for constructing meaning is that Mr. Archer does not remain consistently "fixed" ; rather the meaning associated with service use is plagued by inconsistencies and incongruities.

A second important issue introduced by Mr. Archer regards the impact of his own advancing age and recent retirement in positioning his response to the caregiving role. Specifically, the caregiving role is assumed within a context of decreasing power and increasing vulnerability. He is acutely aware that he is no longer viewed with the same respect that he has been accorded in the past.

CHAPTER 7

CONSTRUCTING THE CARING RELATIONSHIP

INTRODUCTION

Through the process of reconstructing the stories of the preceding four individual's, a background question was always present. Specifically, how did my understanding of each individual participant help to develop broader insight regarding how the experiences of living with a memory impaired partner interface with the use of services? I contrasted and compared aspects of each person's story in order to highlight the differences and the similarities. Then, as main ideas emerged, I `checked' them out against the experiences of the other participants in my study. Gradually a framework for organizing my understanding began to take shape which focused on the importance of `positioning' for constructing meaning.

By positioning I mean the process by which our identities and ourselves as persons come to be produced by socially and culturally available discourses (Burr, 1995). People are `positioned' through the forces of `discursive practices' and the individual's subjectivity is generated through the learning and use of these discursive practices (Davies and Harre, 1990).

> ...[T]he term discursive practices is used for all the ways in which people actively produce social and psychological realities. In this context a discourse is to be

> understood as an institutionalized use of language and language like signs systems... Discourses can compete with each other or they can create distinct and incompatible versions of reality. To know anything is to know in terms of one or more discourses. (Davies and Harre, 1990 p. 46)

In other words the person's identity is a product of the prevailing discourses that are culturally available; these discourses or `story-lines' provide the conceptual, or interpretive repertoires with which we can represent ourselves and others (Burr, 1990 p. 141). There are many `story-lines' available through which we can make sense of the world and these story-lines are not necessarily compatible. Davies (1992) notes that "the choices I make in any current moment will depend on the story-line I take myself to be living out" (p. 69). Discourses provide the possibilities for, and the limitations on, what we may or may not do and claim for ourselves (Davies and Harre, 1990).

Once we take up a position within a discourse, we inevitably come to experience the world and ourselves from the vantage point of the perspective (Burr, 1995; Davies and Harre, 1990). However, at least a notion of choice is involved since there are multiple discursive practices in which each person could engage. Therefore an individual emerges through the processes of social interaction not as a relatively fixed end product but as one who is constituted and reconstituted through the various discursive practices in which they participate (Davies and Harre, 1990 p.46).

The notion of positioning moves beyond the more traditional concept of `roles' where people are thought of as:

> occupying pre-ordained societal `slots' that come with a pre-written script or set of

> expected behaviours which people somehow slip on like an overcoat over their `real selves' (Burr, 1995 p. 140).

Similarly, it contests the conventional view of `identity' as fixed and consistent. Rather, positioning implies a dynamic process (Davies and Harre, 1990; Burr, 1995) which opens up the space for understanding seemingly contradictory actions and responses.

> Subjects are constituted discursively but there are conflicts among discursive systems, contradictions within any one of them, multiple meanings possible for the concepts they deploy. And subjects have agency. They are not unified autonomous individuals exercising free will, but rather subjects whose agency is created through situations and statuses conferred on them. (Davies, 1992, p.34)

While there are different and competing discourses, not all circulating discourses are of equal importance. Rather, some have a privileged and dominant influence on language, thought and action. These `dominant' discourses may be so familiar that they are taken for granted and recede from view and are therefore hard to question (Hare-Mustin, 1994 p.20). The narratives, or personal stories, of the individual can reveal which belief systems, or discursive practices, are being used to make sense of the world.

How does this understanding relate to this study? When I began this project I had questions regarding the self perception of spouses living with a cognitively declining partner. In particular, I wondered if the `well' individual defined him or herself as `caregiver' and, if so, how did this label of `caregiver' get constructed? What emerged from listening to the personal stories of the participants were the multiple positions from which spouses could assign meaning about their role vis-a-vis their spouse. These positions

depended upon the story-line, or set of implicit assumptions and ideologies, that were being used to make sense of the world.

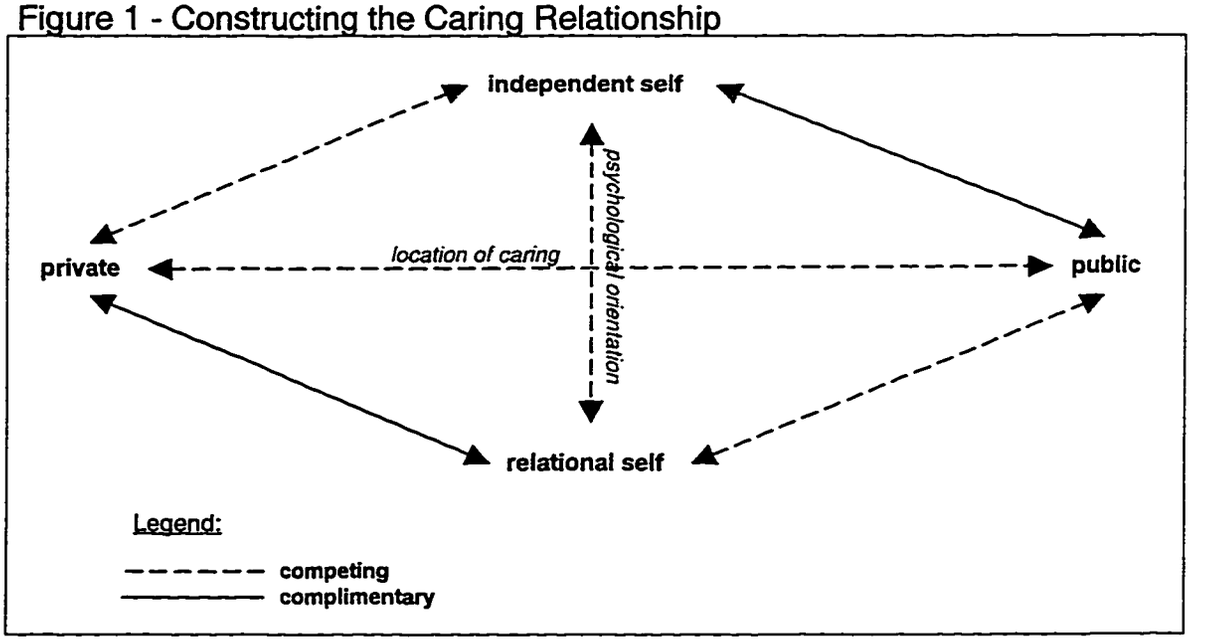
Two intersecting `sites' or `axis' were identified that seemed to have particular importance for grounding the personal sense-making stories or `narratives'. The first site regarded where the caring activities were located. Specifically, participants positioned their perception of their caring activities along a continuum which originated in the understanding of the caring activities as a private responsibility, but then moved toward contextualizing actions within a more social, or public sphere. Each pole of this continuum offered a distinctive discourse for structuring the caring activities. For example, when located within the private sphere ideological beliefs about the family influenced sense-making and caring activities were positioned as `natural' and invisible. At the opposite pole the language of work and public visibility were used to make sense of the caring activities.

The second site for grounding one's actions and perceptions related to the organization of the individual's psychological orientation. Again, a continuum was noted where participant's differed in the degree of importance that was placed between evaluating one's sense of self according to standards of independence or relational connection. Each of these two theoretical endpoints had opposing story-lines associated with it. At one end, the discourse on individualism fostered a psychological orientation that was directed toward independence, autonomy and self-control; one's sense of emotional and mental well-being is assessed by one's ability to take care of one's self. At the opposite end a relational story-line promoted a sense of self that was defined within, and by, one's connections with others; using this story line, one attains a sense of well-being primarily through one's personal

relationships. This site for organizing psychological orientation introduced a gendered interpretation of the structure of caring because the strength and accessability of each story line for personal sense-making was influenced by gender.

Figure 1 summarizes the sites available to the participants for situating their understanding and response to their position vis-a-vis their spouse. It also suggests how the different discourses in each site interacted together.

Figure 1 - Constructing the Caring Relationship



Using this grid as an organization tool, the remainder of this chapter will focus on making explicit how the discursive practices within these sites inform the construction of meaning associated with the use of formal support services by spouses living with a memory impaired partner. I will begin by outlining the discursive practices which position caring as a private activity; this is identified as the `dominant' discourse used for structuring the

activities and perceptions by the well spouses because it was the most deeply imbedded and assumed. Next, I will introduce how the discourses used to organize one's psychological orientation can offer either a complimentary or a competing story line with which to make sense of one's position vis-a-vis one's ill spouse. Finally, I will outline an alternative discourse which positions the well spouse's actions within a more public realm and makes visible the ways that services are structured to maintain the dominant discourse. The objective of this chapter is to begin to illustrate the multiple and contradictory meanings that the use of formal support services can have for the well spouse.

THE FIRST SITE: LOCATING THE CARING ACTIVITIES

The Private Construction of Caring: `Till Death do us Part'

When I listened to Mr. Archer discuss his assumption of the full-time caregiving role, I was struck by the sense of inevitability associated with this transition. As I reviewed the transcripts of all of the participants, this **sense of inevitability** continually surfaced. Specifically, the perception of the caregiving role as a natural extension of the marital role was expressed by all of the participants in this study.

> and then....I *had* to look after her [wife], she's been about two years this way. (Mr. Cashin - emphasis original)

> Oh I'm not patting myself on the back, I just feel that...well what are you going to do, I mean, you have a person that is really dependent on you, WHAT ***ARE*** YOU GOING TO DO? And I love her and I will do what I can for her as long as I can,

or what is best - pretty simply, just stupid old fashioned you might term it now (laughs) Yes [I'm doing what I would expect of myself] And I would, exactly what I would expect she would do to me. I think that's what's called a good relationship. (Mr. Lowe)

Most participants made explicit reference to their wedding vows.

She had looked after me, she had given me nice children and made a nice home, now it's my turn and that's what it was, and our marriage vows said until death do us part, why should I put her in a home...Isn't that what marriage is all about? (Mr. Malloy).

I'm responsible for her. I made that promise until life do us part... (Mr. Cashin)

...I feel I'm obligated to care for her. And uh.. uh, as I told her the other day, you know, it's in sickness and health, for better or for worse, you know, and I said "so things aren't so great right now, but this is part of the deal that goes with the territory" - you know, that's what we committed ourselves to fifty three years ago... so I mean I love the woman dearly of course, quite dearly, and she's, she's been a great strength to me and her life has been my life, we have..we're pretty private kind of people (Mr. Lawson)

...well, I think if, if ever you've been married to a person for that long a time, you

automatically do that...It was part of marriage as far as I was concerned. (Mrs. Knight)

Although there were frequent references to the emotional connection with their partner ("I love the woman dearly of course") underlying many of the responses was also a sense of obligation.

I feel I'm obligated to care for her (Mr. Lawson)

It's my turn to look after him...that's the bargain (Mrs. Macneil)

She's been a great strength to me... it's only right that I should look after her now. (Mr. Lowe)

He was a good husband and father, oh my god. We were so happy in this house. He deserves to be looked after in this way. (Mrs. Deboni)

Only one participant challenged the expectation that he assume responsibility for his wife's care. After outlining the personal cost of caring to him emotionally, Mr. Green acknowledged that he had considered opting out of the responsibility. The consequences of this move would be high; he would "cease to have sons".

I don't know but if I packed up and left my wife, my sons would think I had, I played a pretty dirty deal. But I could say the same for them of course, because we really

don't need to be in this position with uh, if there was some cooperation...I feel like it at times mind you, going out for the day - and I could, there are several women I could go to if I felt so inclined to do that. But...I...it may come to that, it may come to that. (Mr. Green)

In other words, Mr. Green named the repercussions associated with refusing the `choice' of caring for his wife. In doing so, he made explicit the hidden pressure to assume this responsibility. Additionally, he alerted me to the power behind the assumption that caring is a natural extension of the marital relationship when I reflected upon the sense of outrage that I initially felt listening to Mr. Green talk.

My first point then is to highlight the importance of the belief that taking on responsibility for caring for one's partner is a 'logical' extension of the marital vows. This belief grounds the well spouse's response to his or her partner's illness. Specifically, an underlying assumption maintained by all the participants in this study was that based on their marital relationship it was their responsibility to assume a `caregiving' position vis-a-vis their partner should s/he become ill. Although the language of love and reciprocity could be used to cushion this response, the bottom line was that participants demonstrated little recognition of any choice in their actions if they wished to maintain their status as a `good' husband or wife. This sense of responsibility related to the marital vows persisted unquestioningly for all but one of the participants even though most acknowledged at some point during the interview process that their partner was "no longer the person I married"; that person was "no longer with us".

This conclusion is not surprising and is consistent with findings from other research.

For example, Ungerson (1987) suggests that at an ideological level, marriage is regarded as the supreme caring relationship rivaled perhaps only by the mother/infant bond (Ungerson, 1987 p. 53). Similarly, "principles of selection" have been developed which identify spouses, particularly wives, as the pre-eminent carer (Bond, 1992; Walker, 1991; Cantor, 1983; Johnson, 1983).

Not only did participants tend to see themselves as the most "obvious" choice of carer, but additionally, there was an assumption that they were also the most qualified; almost all of the participants referenced the intimacy of their relationship with their spouse as placing them in a better position to respond to their partner's needs. Mr. Archer referenced it as a "sort of mental telepathy" while Mr. Malloy noted that:

> it's common, it's human nature eh. I mean after fifty years you, you practically know when they're going to take a breath [laughs and then sighs]

Similarly Mrs. Macneil qualifies her right to select her husband's helpers

> because I pretty well know who Tom would like after being married for the 48 years and I think that's a long time.

The recognition of the "specialness" of the relationship had the important function of helping participants to reaffirm the value of what they were doing; only they had the inside knowledge and patience to respond sensitively to their partner's often confusingly presented needs. They were the 'expert' in relation to their partner's needs. (I will return to this point later in the chapter).

However, the `specialness' of the relationship also had the impact of further cementing the responsibility for their partner. Mr. Archer voiced it most succinctly when he

noted that as a result of this bond, "I am making myself a prisoner". It became very difficult to legitimize giving over some of the caregiving responsibilities when there was an explicit recognition that the care provided was likely to be inferior to the care that she or he, as spouse, could provide. In other words then, closely aligned with the implicit assumption of the positioning of oneself as responsible for one's partner, was often the recognition that because of the intimate relationship the well spouse was in a position to provide higher quality care for his/her partner.

Interestingly, the intimacy of the relationship seemed to suggest a `license' for fulfilling the caring activities. Specifically, with the exception of Mr. Green, none of the participants questioned that they had the personal qualities or skills to take care of their partner. Rather, the intimate connection superseded all of these considerations; recognition of the relevance of factors related to the well partner's personal disposition, knowledge and skill, all of which would conceivably impact suitability, was notably absent in the stories of these participants. In other words, by virtue of the emotional connection with the ill spouse there was an assumption that the well partner could provide the best care and this assumption superseded considerations about personal suitability.

The implication for service use was that participants were placed in the position of having to balance their own needs against the needs of their partner; attending to their own needs could easily be construed as promoting inferior care for their partner. For most the allegiance was unquestionable.

> You gear everything around - out of necessity, not altogether out of choice, but out of necessity - I gear everything around having to look after my wife....my needs are

secondary. (Mr. Archer)

I have dedicated my life to my husband. (Mrs. Deboni)

It means, yeah, well it means devoting my entire time and effort to make sure that she's not hurt in any way, that she's not upset by anything I do. That if there's something that does upset her, that I can cope with it. I.., I cope with it and smooth it out and take care of it and remove it.... that's about the essence of it. (Mr. Lawson)

I would say that my prime concern now is to see that her needs are met. Obviously my needs are not. (Mr. Lowe)

[my needs] are infinitesimal..the focus was on her. It had to be her. (Mr. Malloy)

My life's been on hold for years. The caregiving consumes your life. The caregiving consumes your life. It takes over entirely day and night. Because that has to become your priority. The other person's life depends on you. And then other duties don't go away, they're still there. So you have to do them as well as you can. And you come last. (Mrs. Ford)

...my sister passed away. And you know, I couldn't find anybody down there, well, maybe I could find somebody to stay with him in that state he was in - I couldn't find

anybody that was suitable, that I thought would be suitable to stay with him. So I missed the funeral. [moment of silence] But that's alright, [my husband's] needs come first. (Mrs. Macneil)

In other words, there was a clear understanding of what their positioning as `caregiver' entailed - the devoted attention to their partners' needs, even if it meant having their own needs go unmet. To even suggest otherwise was viewed as "selfish".

...as I say, sure, I'd like just to get away from the , from the...from the uh..continual..caregiving for want of a better word. I don't do that in a selfish sense... I'm not... I feel guilty about feeling that way, you know... but I suppose one shouldn't feel guilty about it, it's just something you have to face up to (Mr. Jones)

it's most frustrating, terribly frustrating. I'm not selfish now. Um.. I very much miss the activities that we did, going to the cottage, going ourselves there and going down to Florida for a month, we used to like that....going out to visit people. So...on a selfish note, I miss all that, going out for dinner and things like that. But I miss the...more in-depth companionship - that's probably a good way to describe it - with her. She's not the same person. (Mr. Lowe)

Well, I suppose I could [enjoy life more] but I don't want to be selfish about it, I uh..I, I'd like her to to go out too, but..in her condition nobody wants to be around she's not a friend of anybodies... You can't expect them to. Isn't that a down to earth way of looking at it? (Mr. Cashin)

And yet, that this caring stance was problematic was apparent from every participant's description of their experience. For example, Mrs. Knight described it as "pure hell", Mr Cashin identified the situation as "impossible" and indicated that he was having the worst time in his life, and when asked how he would describe what it's been like for him Mr. Lawson suggested that only "nasty language" could adequately express the way he felt about it.

In summary then, examining the dominant discourse on caring reveals three important facets. First, there is implicit understanding that the positioning as spouse mandates that the `well' spouse assume responsibility for his or her ill partner; this is made explicit in the `for better and for worse' part of the marriage ceremony. Second, this `mandate' is legitimated by the perception that the intimacy of the relationship results in the well spouse being positioned as not simply the most logical, but also the most qualified, person to take on this position. Third, when a partner is ill, his or her needs automatically supersede the needs of the well partner; attending to one's own needs becomes a source of guilt and self criticism. This then, is one `grand narrative' or story-line that provides a set of guidelines for framing the personal response to a partner suffering from a cognitive disorder.

Positioning within this discourse has implications regarding how meaning of formal support can be interpreted. Specifically, service use may be set up as a sign of failure. Because this meaning became more visible when participants used an alternative discourse for positioning their activities it will be briefly identified here and pursued with more depth later in this chapter.

Mr. Malloy's immediate association of formal service use with placement in a long term care facility drew my attention to the close connection between these two seemingly different issues. Other participants elaborated upon this link. Several viewed service use as simply a precursor to placement. For example, Mr. Jones indicated that he finally initiated the involvement of a home support agency as an interim plan until placement in a long term care facility could be arranged. Mr. Cashin cited a similar reason:

> Well, if I, if I, I think I better try it that way first [involve a home support worker] because somebody will say I told you so, something like that...if I went ahead and tried to get her into a ..a regular nursing home because I don't think they'd let her in there.

Although he repeatedly voiced pessimism that it would actually help, service use was positioned as a last ditch effort used primarily to demonstrate that his intentions to make the situation work were honourable.

For some of the participants then, utilizing external supports was explicitly linked to placement. For all, placement was pejoratively viewed. A clear dichotomy surfaced between maintaining one's partner at home versus having him or her admitted into an institution. Placement was associated with `abandoning' one's partner. This perception was maintained despite objective evidence to the contrary. For example, of the three participants whose partners were institutionalized all remained very active in his or her care: Mrs. Cook organized her day in order to insure that she was available to feed her husband all of his meals at the nursing home; Mr. Malloy visited his wife daily to oversee her nursing care and provide companionship; and Mrs. Knight spent personal time with her husband most

days and became very active as a volunteer in his activity programs. Despite this continued commitment and involvement all three of these participants voiced their perception that they had failed. Somehow they had not lived up to the `bargain' they had made with their partner.

Mrs Deboni vehemently vocalizes her understanding of nursing home placement. After discussing the personal harm to herself that she was experiencing due to her caregiving activities - noting the exhaustion associated with being required to awaken every two hours all night long in order to turn her husband, and the constant pain in her ankle and swollen arms resulting from the physical strain of this continuous turning - she concludes that:

> But I will never, never take my husband away from the house, never. They have no time for those patients. They don't have enough help, hospitals, for them. Especially when you have to feed them. [My husband] would be dead a long time ago....And you see that the nursing homes and things like that is really demonstrating that lack of caring and lack of being human. (Mrs. Deboni)

Her statement captures the understanding that her husband's survival depends upon her. It also explicitly equates placement with lack of caring.

Although less extreme and perhaps more disguised, I questioned that the same pejorative views connected with placement were, at least initially, also associated with service use. This is because of the frequency with which questions referencing formal support utilization were interpreted in relation to placement by a number of the participants in addition to the explicit links made between the two by some of the participants. In other words, although placement signified the ultimate failure to respond to one's partner in the manner that one `should', the use of formal support services at least for some, seemed to

conjure up similar negative connotations. Positioning oneself within the discourse that stipulates that caring is an extension of the marital relationship and therefore a private affair, may set up the use of formal support services as a sign of failure, a public manifestation that one doesn't `care'.

THE SECOND SITE: PSYCHOLOGICAL ORIENTATION - WHO AM `I'?

All of the spouses assumed a sense of responsibility in relation to their ill partner which was grounded in the `grand narrative' tentatively entitled `Till death do us part'. However, differences emerged regarding the consistent `fit' of this story line for each participant. Closer examination of each person's narrative revealed the importance of culturally available discourses related to the development of a sense of self for offering another story line for making sense of the experience of living with a cognitively declining partner.

It was Mrs. Cook's story that alerted me to the availability of two opposing discourses for organizing one's psychological orientation. Because it had been my intent to centre this study on the experiences of the well spouse, I was initially frustrated when my attempts to do so failed with Mrs. Cook. Specifically, from the onset Mrs. Cook repeatedly responded to my directed questions about her experience with references to her husband. I wrestled unsuccessfully to develop some sense of Mrs. Cook outside of her relationship with her husband. When I finally asked her directly, she too was unable to locate a position for her `self': "I honestly don't know" she wept.

Later, reviewing the transcripts of the other women, the tendency to centre attention

upon an `other', generally the partner, continually surfaced. For example, none of the women responded to the question "What's it been like for you?" from the subject `I' position. Rather, like Mrs. Cook, two women started by backgrounding their husband's symptoms, another woman made reference to when "we started having health problems" , Mrs. Ford began to talk about "the caregiver", and another woman positioned her response in relation to the disease: "It was hard at first to establish what was going on". These initial openings were in marked contrast to most of the men's responses. Here for example, four of the men began by offering background information about themselves in order to develop a context for understanding their reaction; one of these men, Mr. Cashin, refused to turn on the tape-recorder until he had spent over thirty minutes detailing his personal background in order to position how "I got to where I am is right now". A gendered interpretation of the experience began to emerge that was grounded in how one attained and maintained a sense of self.

This introduced the presence of other story lines for making sense of the experience of living with a cognitively declining partner. Specifically, two opposing discourses for structuring one's sense of self became important. In one story-line, which for social and political reasons is taken up more consistently by women (Miller, 1986; Greenspan, 1993; Kaschak; 1992), one's sense of self is developed and maintained in relation to others. In the other story, the more traditionally propagated one, a sense of an independent, autonomous self is fostered. Gender influenced which story is more accessible to an individual.

The following section will examine how the discursive practices which produce a

sense of self were employed to ascribe meaning to the use of formal support services. First, I will explore how the importance of relationships for structuring one's sense of self played out in the wives' interpretation of their experience. Next I will examine the implications for meaning making associated with being positioned within an opposing discourse which fosters ideals of autonomy, independence and self-sufficiency.

The Relational Self

In our society, female identity is "structured according to the demand, externally imposed and often deeply internalized, that a woman is a person only in so far as she is in relation to an `other'" (Greenspan, 1993 p.221). In other words, the story- line that is most available to women in our culture regarding their psychological orientation is one which fosters a sense of self that exists only in relation to an other; the `I' can be defined only in connection to the `you'. It then becomes the woman's `job' to insure the presence of `you'. This means that women are "socialized to defer their needs to others, to care, to listen, to connect and to be preoccupied generally with the well-being of others" (Jack, 1991 p.3) because it is through this `taking care' of the relationship that one's sense of competence and self esteem can be assured (Miller, 1991; Gilligan, 1982).

This story line clearly exerted power in how the women made sense of, and responded to, their experience. Specifically, the importance of the relationship with their partner and the ways in which the women judged themselves by their ability to preserve it, provided a grounding to many of their day-to-day practices that was not found in the stories of the men. Mrs. White most explicitly makes this point when after describing the

historically problematic and unfulfilling nature of her relationship with her husband she voices her perception that leaving was not an option; she must "make a go of it" or risk living with the "embarrassment" of her failure.

One way that the underlying assumption regarding the importance of connections played out was in the women's internalization of some of their husband's symptoms . In particular, issues regarding their husband's continuing ability to recognize them were raised by all of the women as having the power to validate, or unsettle, their internal sense of self. For example, Mrs. Cook interpreted her husband's inability to recognize her as signifying that something was `really' wrong and she no longer knew where she fit, while Mrs Ford initially responded to the same symptom with shame and hurt that her husband seemed not to love her any more. Conversely, even in husband's who were no longer verbal, the women read personal validation into actions and responses that to me as an outsider could be overlooked as insignificant; Mrs. Deboni beamed when she was finally able to get her husband to make eye contact with her while Mrs. Ford interpreted her husband's almost imperceptible grip-tightening as a sign of response to her. Talking about her commitment, Mrs. White described the following moments as affirming (although she also questions her interpretation):

> And then other times, he will say to me... "I like you" ..."where did we meet? Did we meet at the hospital?" So, as if he's met some stranger, some strange woman and he more or less goes back to his days of courting or something you know....I will say to him "do you know who I am?" and he'll say "well, I know your face but I have a hard time with names you know". So..he'll, he seems to sometimes, you know, he

seems to know but..you never know with him, you know. (Mrs. White)

Husband's recognition then, far from being seen as an external symptom, contained a personal interpretation which could be either validating or disconfirming for the wives. When compared with how the men in this study talked about their wives's recognition marked differences were noticed. First, although several of the women focused on their husband's failure to recognize them as a personally meaningful issue, none of the men spontaneously highlighted this symptom. Second, when asked specifically whether his wife still recognized him, several of the husbands denied that this was a problem although some of these same man subsequently relayed incidents which referenced their wife's failure to recognize them. Third, of those who did acknowledge that their wives no longer recognized them, their response was to rationalize this as simply another symptom of the disease process; a symptom which saddened them but was understood. None of the men said anything that suggested he took personally his wife's lack of recognition.

The importance of preserving the relationship in practical terms, seemed to translate into protecting one's husband's sense of self. This surfaced as an important guiding principle used by the women to make sense of their general experience; quoting Mrs. Cook it meant "taking over more and more while trying to keep him from noticing". It also meant minimizing problems to others in order to avoid "embarrassing" one's husband and maintaining the facade of their partner's input in decision-making.

This became especially apparent to me when I reflected upon the interview process with the Macneils. Throughout more than three hours of `formal' interviewing, Mrs. Macneil smiled benignly and joked with her husband while they both presented a picture of

togetherness, satisfaction and successful management. Rarely did she contradict her husband's perception that the situation was not only under control but, in fact, improving. Only when talking about their devastating treatment experiences with the medical profession did Mrs. Macneil become angry. Otherwise there was a light, congenial atmosphere. For example, recognizing her husbands repetitiveness, Mrs. Macneil laughingly responded:

> Oh yes! But no, as far as that goes, my goodness, I can, I can't remember sometimes what day it is neither. You know. My memory's good but you have to get the paper and make sure. Yeah, he's got trouble like that. (Mrs. Macneil)

The tendency to downplay her husband's difficulties, often by normalizing them, persisted throughout the interview. However, when I stepped out of the apartment to leave, Mrs. Macneil followed. She shut the door behind herself and began to cry. During the next forty minutes she proceeded to describe how desperate the situation really was but acknowledged she could not say these things in front of her husband; he was such a "lovely man" and she "did not want to hurt him". In contrast to the picture presented earlier of a man who was relatively self-sufficient, Mrs. Macneil described the need to provide extensive support and supervision. However, perhaps lest she be seen as complaining, she then hastened to affirm her `blessings'; "as long as he is living and I have him with me, I thank God every day of the week".

The emphasis on protecting one's partner's sense of control and involvement in decision making was present in all of the women's stories. This focus on protection limited the use of services in a number of ways. First, several of the women noted their reluctance to use services that their husbands perceived as belittling. Husbands' negative response to

services, both actual and anticipated, dictated at least initially all of the wives' unwillingness to accept services; as expressed by Mrs. Cook, only in circumstances where potential physical harm clearly outweighed damage to self esteem could service use be pursued irrespective of one's husband's wishes.

Second, there were few attempts by any of the women in this study to frame the use of `caregiver support services' according to their own needs. Rather, a sense of entitlement to support based solely upon one's own needs was generally (although not entirely) lacking. Instead the primary focus remained, with few exceptions, on the needs of their husbands. For example, Mrs. Macneil described the restrictions created by her husband's deterioration on her availability to attend Mass regularly; she mourned this loss and yet when talking about the minister's monthly visits to the couple's home, these visits were positioned solely in response to her husband's needs. Similarly, Mrs. Cook berated herself for not utilizing services because this might have prolonged her ability to manage her husband's care at home; she presented herself as not the worthwhile recipient of services but rather an object for fulfilling her husband's needs.

Husband's needs then, were accorded priority. Service use became acceptable primarily when it was presented as the lesser of two evils. For example, in light of concerns regarding their husband's safety when left alone, several of the women considered and/or utilized support services to insure adequate supervision for their partner while they ran necessary errands. Three of the women felt impelled to explicitly point out that they used the time to accomplish mandatory tasks rather than for "respite".

Even when personal needs were recognized they took a secondary position to one's

husband's responses for all of the women; specifically most of the women acknowledged as essential their husband's co-operation in accepting services. For example, Mrs. Knight indicated that she "absolutely" felt she needed some time off but would not consider using any home support services unless her husband was agreeable. Initially he was not. Services were not used until he gave his permission.

> I told him [husband], I said you know, I have to go out once in a while. I want to go to the do's that they have at the office, that I really should be attending, after being there all those years. So, and I said, I'd like to see the girls about once a year again too and chat with them. So he agreed to it [having a respite worker] then. (Mrs. Knight)

There were other implications associated with the importance placed on protecting their husband's sense of self. Specifically, to be successful in this `mandate', by definition the work that these women were taking on was required to be hidden; they could not receive recognition of their work **and** they had the extra work of insuring invisibility! The following quote illustrates the vigilance and sensitivity expended by Mrs. Macneil as she attempts to be inclusive about implementing a decision that in reality is being handled without her husband's input.

> ...**we** would like very much - **I** would like very much and Tom would too, I think (laughs) - where ever I go Tom wants to go anyway. So I'd like to get out of here. **I'm** looking for a place, **or we are** looking for a place.... (Mrs. Macneil)

This felt `right' to some of the women. Mrs. Macneil for example indicated how awkward

it felt when her husband thanked her when she was assisting with his care need. She indicated that she "wished he wouldn't thank me" because she was "only doing what I'm suppose to" and felt "bad" that he thought he had to thank her. She doesn't pat herself on the back or anything like that "because, I don't know, I just do it. I'm suppose to do it and I just do it...I don't think I deserve praise".

However, the ongoing attention to their spouses' emotional well-being introduced an element of uncertainty that was extremely distressing for many of the women. Specifically because their husband's reactions could never be anticipated with any degree of certainty, the women consistently described their current experience with metaphors such as a "balancing act" , " being on edge all the time", "walking on eggshells" and "walking on pins and needles". For example, Mrs. White describes her experience:

> I feel like, like now, I'm all on tender hooks. I feel like I'm on a tread mill, all the time, all the time, and I can't get off this thing. You know. As if, as if I'm running out of time!... I don't think [my daughter] realizes how I am agonizing, how I feel like I'm hanging on by edge sometimes, you know. (Mrs. White)

Cumulatively then, the positioning as `protector' of their partner's self image required increased work and stress, while simultaneously affording less recognition of the work they were doing and less opportunity for support.

Interestingly while disclaimers related to their caregiving efforts were common, and all of the women's stories illustrated the steps taken to protect their partners as much as

possible from an awareness of the severity of the situation, simultaneously several of the women railed against the failure of others to see their work. While several men also commented upon the lack of visibility of some of the tasks, with the women the lack of recognition of their work was further complicated by the feeling that they were being judged as deficient by others.

> ...uh, at the beginning it didn't bother me that much but it bothers me a lot now because I feel I'm carrying a tremendous load and it's kind of hard when you get so much criticism from his family and they're doing little or nothing and telling you what you should be doing and what you should be doing...And you feel you're doing everything for this person and then they don't know you. He doesn't even know who I am. (Mrs. White)

This feeling of being judged is compounded for Mrs. White by her husband's inability to recognize her - even he cannot provide validation of her efforts.

Mrs. Knight's story made clearer the double-bind of expectations of invisibility while simultaneously being awarded recognition. Specifically a vulnerability to being judged ran through her story. To counter this, she repeatedly defended her actions by reasserting her husband's control in all decisions; she makes explicit the premise that he, not she, `should' be in control and that she will be judged harshly should she usurp him. For example, she was insistent that it was her husband's decision to enter a care facility but she worried that people might think that she "made" him go, or conversely, would question the adequacy of her care given that her husband preferred to go into a facility.

How could I explain that [feeling hurt about her husband's decision to go into the

home] Well, actually, I kind of felt that...well, all I had done for him wasn't good enough. That I had been a failure. [beginning to cry]...but I should be glad for him, if he's happy there. Let's face it, Deborah, I figure, I'm a very happy - lucky person I should say - that he decided on his own free will that he wanted to go back. Because there are enough people there, when it comes to the nitty gritty, the person doesn't want to go and they're having an awful time getting them admitted and getting them to go. At least it was his idea. But see that's another thing that really bothers me. That people will say "oh well, you couldn't cope any more, you tried to get rid of him, you put him in there". [in a forceful voice] **I DIDN'T PUT HIM IN THERE.** That was ***HIS*** **DECSION** not mine you know.

Mrs. Knight was in a no-win situation; the precarious balance that she is attempting is made visible. The challenge seems to be to both foster the illusion of her husband's control while simultaneously insuring that her rights are respected. For example, she tells the following story about a breach in her relationship with her sister-in-law resulting from her anger that she was being judged.

As a matter of fact, I ordered her out of the place one time and .. He started to have troubles saying things and it really frustrated him. So, I would fill in - it's not that you're filling in for somebody that has a speech disorder, like stuttering or what have you, because I realize that's the worst thing you could ever do for a person that stutters. Try to finish the sentence for them. But... he would get so frustrated, and I could see the frustration, and I'd finish. And one time she looked at me and she says, "I asked him, I didn't ask you!".. And it just hit me the wrong way, needless to

say. So, I said "if you think that you'd like to take over the care of your brother", I said "you're bloody welcome to it". I said "don't ever contradict me and what I'm trying to do for him. I'm still married to him". "Well, you shouldn't finish his sentences". I said "Listen, I've had enough of you. Just"... well, I won't repeat what I used, but... out the door. I was mad enough. I thought, I don't have to take that from you and that's all there is to it, so I completely ignored her. So uh .. [to herself] how did we get together? ... Oh, I found a note under the door, saying that we can't go on like this for ever, what are we going to do about it? So, I wrote her a note back, saying I feel that yes we should make up but just stay out of what I try to do for your brother, don't give me any orders and never tell me what to do because I'm the caregiver, you are not, you're at work all day. (Mrs. Knight)

Similarly, although Mrs. Ford repeatedly referenced her attempts to maintain her husband's dignity and perception of control, she also expresses anger that her activities are invisible.

Um, they see the person who needs the care being very vulnerable and they say "oh you should do that or you shouldn't get angry or if you loose patience"...They're judging things on one instance and they're not seeing the whole picture.

Mrs. White describes her perceptions that she is being criticized for being overly protective but then hastens to position her response as a `natural' empathetic response.

[my daughter] says I'm protective, I try to do too much for [my husband]...but that's the kind of person I am you know. I think I do sometimes but he's not able to do

anything! Now. He's not able. But he's so demanding, you know very demanding, and um..but anyway, I think he's had a lot of problems in his life you know...[she begins to discuss her husband's traumatic upbringing]

Although the desire not to have their partner hurt was certainly a strong motivator, it wasn't simply "good will" or some sort of "maternal instinct" that motivated the women to protect their husband's. Rather, for some of the women, more overt attempts to take over control met with resistance from their partner. For example, Mrs. Ford described the recriminations she was subjected to by her husband when she attempted to seek treatment for him after he fell down the basement stairs:

> I finally convinced him in the afternoon that I had to take him to see the doctor because there was a blood blister that was getting bigger and bigger and bigger and I didn't know whether we should do something for it and of course, I knew we had to give him something for the pain and all the way to the hospital he was telling me "you're ruining our marriage" (Mrs. Ford)

The women in this study alerted me to the recognition that it was not simply an attack on their personal integrity that was the concern. Rather, attempts to take control over their husband could pose serious physical risks to some women's safety. Four of the women talked about being fearful of their husbands. Two quickly inserted that their husband's had in fact never become violent but as noted by Mrs. Cook, "you never know". The other two women described repeated incidents where they were physically intimidated and assaulted.

For example, Mrs. White notes that her husband could get "nasty" and that was his way of maintaining control. Throughout the interview she tells of numerous incidents such as being bitten on the face by her husband, having her wrists twisted, being grabbed and hit, and being threatened with a butcher knife.

> And another thing he does, he's got a thing about flash lights....And he takes the flashlight and puts the light on and holds it against your face and push you around. Now he's a big man, he's over six feet tall. And he puts his arms around my neck like this, oh, he's threatened to kill me more than once and he did split my head open... with a big heavy telephone, not a light one, it was a big heavy one like that and he cut my head open this big [demonstrating] (Mrs. White)

She talks about being "terrified, absolutely terrified" of her husband because she is "afraid of what he'll do". She acknowledged that she felt her husband had "always tried to control me by intimidating me with his screaming" and indicated that he had "always been a man that's got to be in control... and he still wants to do that". She notes that her husband "threatens me if I don't want to co-operate with him" and that he got nasty "when you try to tell him to do anything".

> And, I was having so much trouble with him. All the time. And uh, I reached the point where I was afraid of him, threatening me you see, all the time, and my nerves, just got so bad, and I got so edgy and everything and I keep wondering what should I do and what shouldn't I do...[voice fades] (Mrs. White)

Although prior to the disease there had been two or three occasions that her husband became violent, his aggressive outbursts had accelerated and become increasingly frequent since he was diagnosed. Medication had been tried; currently he was quieter as a result but a previous attempt to medicate her husband had resulted in a marked increase in his aggression - Mrs. White notes that for over two weeks she was "afraid" to go to sleep and stayed in a chair in the living room all night holding an umbrella for protection.

Interestingly, in contrast to the literature on wife abuse which often communicates to the abused woman that she `should' leave, the directions given to Mrs. White included suggestions that she "hide the butcher knife".

Like Mrs. White, Mrs. Ford also went through a period when her husband was physically aggressive. She identifies this as standing out as a particularly rough time in the course of the illness. She describes that period as

> really bad. Because I never knew when he'd punch me, pinch me, scratch me, pull my hair, tear my clothes. Usually it was, he was hallucinating when these things would happen. But I think the medication that he was on certainly contributed. That's why after a while I decided to stop all the medication.

In other words, concerns about personal safety were present for several of the female participants. This concern, and in some cases active physical aggression, necessitated that women assume control over the situation in a more covert manner; it was not simply an internalized perception that while they were expected to `take over' they had the additional task of making it look like they weren't. In fact, there was some awareness that one's

husband's aggressive outbursts could be seen as reflecting personal inadequacies.

From this perspective, enlisting services when one's husband was not co-operating could mean *increased* work and potentially finding oneself in a threatening situation that was out of one's control. Mrs. Knight, whose husband was not aggressive toward her, describes her failure to assert her need for support.

> To be perfectly truthful, I don't think I was strong enough to say that. I should have spoken up for that and said well listen, this is the way it's going to be, but then I was always afraid of upsetting him, that he would be more difficult. So I didn't do it. (Mrs. Knight)

In summary, the story-line that positions women's sense of self as predominantly in relation to an `other' could be heard in the personal narratives of the women in this study. Practically, adhering to this story line promotes the importance of protecting one's husband's sense of self as a guiding principle for defining the actions of women whose husbands are cognitively declining; this aspect of the experience was not emphasized by the husband's caring for their wives's. To successfully implement this principle requires that the women accord priority to their husband's needs. This raises questions regarding where the `concept' of `caregiver need' fits into the use of services for women.

According priority to the needs of the partner, rather than themselves, was consistent with both the understanding of what a wife does when her husband becomes ill and what a woman does in a relationship. It also fit well with the pragmatics of the situation in which wives were being expected to cope with physically stronger husbands whose undependable

behaviour could be intimidating and threatening. There were few contradictory messages here - as both a woman and a wife the expectations of selflessly attending to of all of one's partner's needs was assumed. In other words, the dominant story for producing an understanding of a `good' woman closely parallels the narrative which constructs the caregiving role as grounded in the private domain of the marital relationship. The two discourses compliment one another and both send congruent messages to women which limit the use of services for personal support.

The Independent, Autonomous Self

Conversely, the stories of the men introduced a competing discourse from which to construct meaning about the use of support services. In contrast to the women, the relational self story-line did not appear to exert particular influence in the men's personal narratives. Instead, an opposing discourse which cultivates the ideal of an independent, autonomous self appeared to hold more power.

This story offers a contradictory version of `reality' to the dominant discourse which structures caring as a private affair. Positioning within this latter discourse requires selfless giving to the ill partner and recognition that his/her needs supersedes the well partner's. Conflicting with this, is the set of beliefs and ideals promoting the notion of an `independent, autonomous self'. For example, traditional theories of psychological development promote personal autonomy and separation from others as an ultimate goal for psychological maturity; individuals [sic] aspire to develop a firm, separate sense of self which is assumed to exist independent of the individual's relationships (Jack, 1991).

> The achievements of the autonomous individual are understood in terms of self-realization, the gratification of one's needs and desires, the full "utilization" of one's distinct human capacities ... [quoting Locke] "Freedom from dependence on others means freedom from any relations with others except those relations which the individual enters voluntarily with a view to his own interest" (Lichtman, 1990, p. 34-35)

Mr. Lowe explicitly addressed the conflicting positioning:

> About the only thing that they [referencing helping professionals] deal with me is they kept telling me to look after myself - to try and stay healthy. But there's a lot of tension in this business... a lot of tension. And I've lost weight, get irritable, etcetera, etcetera. To tell me I was important, and to try to take care of myself, whatever the means, I don't know... I knew perfectly well I should! (laughs) It was good advice, well meaning advice and I understood it. But you can't exactly apply that kind of advice. (Mr. Lowe)

Similarly, Mr. Cashin concurred that a critical struggle for him focused on trying to balance his own needs with looking after his wife's; "That's it! That's it! That sums it up" he responded forcefully. This dilemma, balancing personal against partner needs, was rarely intimated in the women's stories. The men's stories then, introduced the availability of another discourse to assist in making sense of the experience of living with a cognitively declining partner.

This story line was used in at least two ways to assist with sense-making. First, it provided a language to both recognize and begin to legitimize one's own needs. Specifically, several of the husband's were able to ground their use of services in relation to identified personal needs. Mr. Archer for example, mostly used respite to "chase around and get all sorts of odds and ends done" but he was also interested in obtaining further respite in order that he could continue to go swimming. Similarly, Mr. Malloy tried to attend to his own needs for exercise through his wife's participation in the day care program. Mr. Lawson used the homesupport services in order that he could continue his part-time work while Mr. Lowe had someone stay with his wife periodically so that he could maintain his involvement as a volunteer; this at least partially addressed the void in "intelligent conversation" resulting from his wife's dementia. In other words, positioning within this story line offered an acceptable language for raising questions about the dominant discourse on caring because it validated one's right to attend to one's own needs.

> I felt relieved quite frankly [when somebody began coming in from the home support service]...I was just about at the point where I needed some outside commitment to be sure that I had coverage. Because um, when I commit myself to these hearings, um getting a day for a hearing is bad enough when you've got two lawyers involved and about 20 witness and two other board members - it's hard to find a common date. And I just could not afford not to be there you know, I would feel terrible... And I just said to [my wife]. I just , I said "I'm doing it [hiring a homesupport worker] for my sake. I wouldn't be easy in my mind if I just walked out of here and left you alone for a whole morning or a whole day". I just, I wouldn't be happy. (Mr.

Lawson)

Second, this alternative story for making sense of one's experience introduced the possibility of establishing boundaries regarding one's caring activities. This was brought to my attention by Mr. Malloy's perception that he accompany his wife into the public washroom as laughably ludicrous while Mrs. Ford saw the same behaviour as an expectable and obvious response to her husband's difficulties. Similarly, "I do everything" seemed to have different meanings; in particular for the men it referenced household activities and "directing", as opposed to personally doing, their spouses personal care needs.

"You have to sort of direct everything" (Mr. Lowe)

My role is keeping the ship afloat at this point in time because if anything happened to me, within a week at least it would sink....getting dressed, that's a bone of contention because - there again, I suggested to her that before she, when she gets dressed before she puts on her dress or shirt, that she come and check with me with respect to her slip you know. And I've time and again tried to get that...Well, and I said at night, before you do anything now you ask me because I can't keep my finger on all of things. If I did, I would..I don't know what I would do. (Mr. Green)

All of the men referenced their role in terms of the decision making responsibilities that now belonged solely to them. For example, Mr. Green described his role as "I have to make all the decisions now" , Mr. Lawson notes that"I just sort of run the show" , while Mr.

Jones notes that "everything revolves around me now, absolutely everything".

> You know. I am her mind such as it is. I have to cook, I have to buy the groceries, I have to do all the housekeeping apart from the cleaning lady who comes in. Uh, there isn't anything that I do not do. I replace her brain, that's about it. And uh, if I was ten or fifteen years younger I perhaps would keep on doing that but I am 78 and heading for 79 and uh, I just can't do it any more particularly since...I am getting older and she is getting...worse. (Mr. Jones)

I note that "everything" does not include references to personal care needs.

Restricting one's interpretation regarding what one was `supposed' to be doing had implications for service use. As introduced in Mr. Malloy's story, it opened up neutral space for service providers to fill. The men's sense of responsibility for `managing' the situation could be left intact and attending to aspects of personal care which were not owned by them held no threat.

In summary then, when positioned within the discourse on individualism, an alternative interpretation of the caregiving process was possible. Specifically, in contrast to the dominant discourse on the structure of caring which sublimates it, this story-line promotes the production of an independent, autonomous self. It provides a language for establishing boundaries on one's `caring' activities and legitimizes attention to one's own needs. In doing this, it offers the opportunity to challenge the dominant discourse . As made explicit by Mr. Malloy one could define oneself as a "caregiver" simply on the bases that one "cared deeply".

However, positioning within this discourse also raised the potential for the

participants to feel conflicted. On the one hand were the expectations of selfless caring for one's partner while on the other hand were the inculcant messages promoting autonomy, self sufficiency, and `strength of character'. This latter perspective assumes an individual ownership and control over the situation that emerged in a variety of ways in the personal stories of the men.

First, expectations of control helped to define the experience. For example, two of the men explicitly queried whether they had in some way caused their partner's problems; as noted earlier, speculating on incidents that dated back more than fifty years, Mr. Malloy described sitting down and wondering "Now what did I do?...Am I the cause of it, am I the problem for it?". Mr. Cashin too suggests his concern that he is in some way responsible for his wife's difficulties.

Along similar lines, many of the men alluded directly, or indirectly, to their sense of responsibility in combating the illness.

> Well, ...I pushed hard for everything I could get as far as testing and examination and everything. We did everything under the sun - getting her on the drug program for example, it's a test program, got her in it. And I think,. the nice part of all this is I can't think of a single that I could have done that I didn't do. (Mr. Lowe)

> I've kind of gone through the beginning stages into a kind of a horrendous stage until we got this thing nailed down. When I reached the point where I was absolutely certain that my diagnosis was the correct one and that the effects of the ailment were so troublesome to me, then I got the medical help. (Mr. Lawson)

On the positive side, as noted by Mr. Lowe, `taking on' the illness provided many of the men with a sense of active purpose. However, it also confronted them with their own sense of impotence. For example, both Mr. Archer and Mr. Lowe referenced their realization that they had been unable to `beat' the disease and spoke despairingly about the sense of helplessness and loss of control that they experienced.

> you can't beat it...**And I don't like that!..** I think that was a lot of my problems in the early stages - the frustration. I wanted to **do** something... I wanted to **beat** it. (Mr. Lowe - emphasis his)

> ...I don't think there is any way that anybody who has never looked after a patient with this type of illness can understand it. The complete helplessness that you feel for yourself...because.. you can't do anything about it. (Mr. Archer)

The use of regimentation and schedules was used to help maintain control over the situation. Staying "on top of things" seemed to be a guiding theme for several of the men.

> So, it's not a very outgoing life in that sense. But I don't mind as long as I can stay on top of things... I've always been an optimistic, uh, positive, cheerful kind of a guy I suppose and I guess that's as I told you before, I'm a survivor and I've always thought in terms of uh, of the positive side of things and I don't dwell too much - if I were to sit down and think of all the horrible things that could happen, I wouldn't last a week. So thank God I guess, I've got that inner strength or stupidity or whatever it is (laughs) that supports me. I've always been a very disciplined sort of

a person. (Mr. Lawson)

I just have to check when I'm washing the dishes and then I, I uh, clean up the table and if she got any crumbs on it, I always take a look at the little bottle that I put the pills in - if there are two in there than I hand it to her and I say "you forgot your pills today" This goes on every other night or so. But I can't complain because it's part of the routine. I have it down, a system there that...well, I always was a guy that did make the best of things, you know, get a routine.... just have to take things in stride. What has to be done has to be done and I'm the only one to do it, I'm the only one that knows how to do it . (Mr. Cashin)

This expectations that one `should' be able to maintain control over the situation opened up the potential for feeling responsible for one's plight. "I am making myself prisoner" notes Mr. Archer (emphasis mine). Similarly, Mr. Lowe clearly states his belief that it is his responsibility to actively work to minimize the impact of the situation.

I think people [referencing caregivers] have got to get up off their butts and try and have people in, and try and phone people and write them a happy birthday card or something like that, to keep in touch will all your old friends and acquaintances. I think it would be absolutely awful if you let everything go. What would you be then? Nothing. You would be a cipher...You've got to make an effort in this life. [pause] But sometimes you get awful tired and you don't want to do it. (Mr. Lowe)

Later, he attributes his decreasing socialization to "I'm not trying hard enough, I guess" and

explains his fatigue as "I'm probably just old". Unnamed is the situational toil of an impossible situation; rather the assumption is that I should be able to cope effectively (and am therefore deficient if I cannot).

To summarize then, emerging out of the discourse on individualism was an expectation of individual control over the situation which was especially pronounced in the stories of the men. They talked about this expectation in a variety of ways including: querying personal blame for causing the disease process; framing the disease process as a `foe' and assuming responsibility for `combating' it; and adhering to schedules and routines as a means of infusing control. The potential for perceiving oneself as deficient, or inadequate, `should' the disease `win' or the situation move out of one's control, was made visible.

Not unexpectedly this story line fostered pejorative connotations associated with `dependency' which could be heard in the stories of most of the participants.

> ...it's degrading for me - to be the object of sympathy from people who.. um..feel a little bit superior because they don't have the illness. At least one gets the feeling that they feel that way. See, it's hard to distinguish genuine sympathy from condescension. (Mr. Archer)

In fact, perhaps recognizing the potential for `misunderstanding' several of the men felt it necessary to quite explicitly position themselves as independent persons; this was accomplished both by self describing themselves as such and by relating stories that demonstrated their independence. Closely associated with this assertion of independence

was the implicit assumption that obtaining any sort of assistance, even informal, was indicative of dependence.

> I'm not a fellow that asks a lot of favors from other people anyway, I try and figure it out for myself...If [my wife] had to go in to the hospital or something, I, I don't know - I'd stay here myself I guess, because I'm kind of an independent. (Mr. Cashin)

> ...I'll talk to the children a bit about the problems, and things, but I try to avoid telling other people about my problems...I don't think it's fair to her [wife] for one thing. What am I looking for, sympathy?... I wouldn't mind a little sympathy, but I'm not going out looking for it. I've always tried to be independent in life. (Mr. Lowe)

From this perspective, the potential for service use to be interpreted as a signal of loss of control was explicitly raised by at least two men. For example, referencing his own reluctant decision to involve services, Mr. Green voices his perception that:

> I realize that once you start this journey with..accepting their services that uh..the road is coming to an end. It's, you get that sense or feeling that there's - and it's certainly, it's the same as going into a home, you give up, you lose your identity....you realize that uh..when you're , when you're accepting them then..you're at their..mercy. That's a very broad term of course. I..we lost some of our independence, now we're dependent on a certain...program. (Mr. Green)

One way of counteracting illusions of dependency that surfaced was to reaffirm oneself as a helper and not a helpee. For example, countering a reading of dependency, several of the participants devoted considerable time in their stories to positioning themselves as **giving** individuals. Mr. Malloy for example introduced his belief that he was `helping the help'. Mr. Cashin's narrative however, was most illustrative of this need to counter any possible interpretations of dependency with assertions of himself as a reciprocating individual. Throughout his story, references to his increasing need for support resulting from his deteriorating health were invariably quickly followed with a story which depicted him in the helping role. Through this process Mr. Cashin seemed to challenge the perception of himself as a `needy' person.

Summarizing this chapter to this point then, two sites containing three story-lines, have been identified which can be used to explore how the experience of living with a memory impaired spouse interfaces with the use of formal support services. The first explores the structure of caring and posits a dominant discourse which structures caring as an extension of the marital relationship and hence a private affair. Intersecting with this site, are the stories which organize psychological orientation. Two opposing stories have been identified: in one the self is viewed as an independent, autonomous being while in the second, identified, as particularly relevant for understanding the women's experiences, there is recognition that the sense of self may be developed and sustained primarily through one's relationships. When related to the use of services this story-line introduces the importance of the ill partner's involvement in decisions to use services and highlights the well partners' key role in protecting the `personhood' of their ill partner. This latter story is

compatible with the dominant discourse which structures caring as an extension of the marital relationship.

In contrast, the story which promotes the perception of the self as an independent, autonomous being - the story which was particularly important for the men in this study - suggests a competing position from which to make sense of the experience. This story provides a language that allows the expectation of total self sacrifice propagated by the discourse on caring as an extension of the marital relationship, to be questioned. However, positioning within this discourse also has the potential to individualize the issues as personal deficiencies.

When applied to the use of services, this story line infers conflicting messages. On the one hand, it legitimizes the use of services required to insure attention to one's personal needs and creates potential space for services to intervene; service use can be framed as enabling one to attend to one's own needs. However, on the other hand, it simultaneously penalizes through the inferences that one `should' be able to maintain control; services are positioned as a sign of weakness. This discourse then provides contradictory readings of service use as signifying both inadequacy and entitlement.

With few exceptions, the women in this study did not speak from this competing discourse. In some ways, this meant that their positioning as caregiver within the relationship held fewer contradictions. However, it also meant that women did not have an easily accessible language with which to interpret their experiences and therefore, had few visible opportunities for challenging the position of the `selfless caregiver'.

REVISITING THE FIRST SITE: LOCATING THE CARING ACTIVITIES

Caring as a Public Contribution: Becoming `caregiver'

As previously identified, all of the participants initially structured their response to their partner's illness within the dominant discourse surrounding the institution of marriage and familism. Gender cut across the construction of meaning in this position; men and women had different discourses available to them from which to produce their sense of self. Thus, two different subject positions have been identified: `husband', and `wife'.

For several participants, their subject position remained primarily grounded in the marital relationship - and therefore `private'. However, Mrs. Ford's story began to illustrate that this was not the only position from which to ascribe meaning. Rather, the availability of an alternative discourse for structuring one's understanding became visible. This new discourse moved beyond the discourse on private responsibility and familial expectation to employ the language of work and social responsibility; it created a story line that situated the caregiving activities within a more public arena.

Using this new story-line caregiving activities are redefined to recognize their public contribution. Responsibility for ill or weaker members of society moves off the sole shoulders of the family, specifically the spouse, and is redistributed as a societal responsibility. The concept of `community care' is broadened to actually include the community and not just the family. Once this move occurs, the well partner's caring activities can be recognized as performing a valuable public service; they are providing cost-effective (sic) and conscientious care to a member of our society. Moreover, as

productive members of Society, caregivers have the right to recognition for their efforts and to assistance with their tasks.

When this story-line was used to construct personal narratives, an understanding of one's caregiving activities emerged which began to recognize the social relevance and importance of these activities. The degree of influence that this story-line had on the personal stories of the individual participants differed dramatically. For some, it provided a relatively insignificant lens through which to interpret one's experiences. However, for others the clash of this story-line with the dominant story-line which situates caring as a private activity, was loudly heard.

Participants' use of language seemed to provide important clues regarding their position on the private/public continuum. Specifically, one way of recognizing a shift to a more public location was in the words used by the well partner to reference both oneself and one's partner. The participant's use of language suggested that three tasks were important for relocating their caring activities from the private realm into a more public arena: the well partner redefined his or her role in relation to his or her partner; a new language was introduced for talking about the situation; and a sense of personal isolation was countered by a sense of affiliation with the group `caregiver'. While I am going to talk about these three tasks separately in fact I saw them as interdependent.

The initial task, redefining one's relationship with one's partner, seemed to occur predominantly through the processes of 'extraordinizing' and externalizing one's partner's symptoms and behaviour. In reconstructing the four case studies, I was struck by the different ways that the participant's made sense of their partner's symptoms. I went back

over the transcripts of all the participants and identified three ways that the participants talked about what was happening to their partner.

First, as demonstrated by Mr. Malloy, several of the men referenced their wives's symptoms in relation to the aging process. Symptoms became simply exaggerations of life long traits: "She was never one to join in particular in that [conversation]" explains Mr. Green about his wife's deteriorating social skills; "she always was stubborn" notes Mr. Cashin as he describes his wife's inability to remember his sister. This way of talking about their partner's illness seemed to preserve a facade of normality which I interpreted as important for allowing participants to continue to position themselves predominantly within the marital relationship.

A second way of talking about one's partner's deterioration was employed by a number of the women, but none of the men. Specifically, several women talked about their husband's deterioration in relation to their own perceived inadequacy. For example, Mrs. Fisher and Mrs. Ford both referenced how hurt they were when their partner failed to recognize them - they queried personal deficiencies - and two of the other women identified similar responses to their husband's deterioration. Similarly, several of the women owned their husband's catastrophic responses as reflections of their own incompetence rather than symptoms of their husband's disease; none of the women questioned the assumption that they `should' know how to handle distraught, memory-impaired husbands. I saw this way of talking about their husband's illness as consistent with the story-line which fosters the belief that one's sense of self is both developed and maintained by ones relational competence. Their talk exemplified the gendered discourse available to women that

connected their psychological well-being to their ability to maintain a relationship with their partner. In this reading the failing relationship is the problem rather than their husband's condition so the issues are internalized.

The third way that the participants talked about their partner's deterioration was to attribute it to an external cause. There are undoubtedly a number of ways that this externalizing could be accomplished. For example, at one point Mrs. White attributed her husbands disruptive behaviour to the stars. Voicing her disappointment when her husband's behaviour deteriorated rather than improved during a trip to his homeland she indicates that:

> I thought he would be better and then I wondered. There was a full moon you know, and the tides and everything, it makes people crazy. And I really believe there is something to that, that people react more at times...(Mrs. White)

However, the most usual way for externalizing the difficulties was done by medicalizing the problems. Accepting the ill partner's behaviour as a symptom of an illness emerged as the primary way for redefining the situation. Labeling one's partner's behaviour as a disease served as a distancing mechanism which allowed the well partner to begin to see the problems as outside him/herself and the relationship. It had the impact of `depersonalizing' the ill partner because it allowed some behaviour to be discounted as merely part of the illness. For example, referencing his wife's verbal aggression, Mr. Jones described his response:

> Well, as any caregiver will tell you, I guess you.. get used to it. You write it off, you don't pay any attention to it or try not to. (Mr. Jones)

This had potentially both positive and negative repercussions. On the positive side, issues such as lack of recognition could be explained away as part of the disease process rather than seen as a personal deficit. For example, referencing his wife's periodic inability to recognize him Mr. Lawson notes that:

> well, I just accept it and I uh, I just try and say well, you know that's me, I'm here. And I'll try and look after you you know. But, sometimes she says "I don't want to be a burden" , you know. She knows that there's something wrong but she can't enunciate, she can't put her finger on it...I suppose I could be angry, I could be hurt and react more to the sense of loss of identity which I might think, I... don't really feel..it's a true loss of identity. I think it's just that she's confused. (Mr. Lawson)

However, on the negative side, the disease label also allowed the well spouse to indiscriminately discount their partner's responses. Responses indicating for example, depression, anger, or annoyance could be relegated as simply `symptoms' of the disease. In fact, there was a danger that almost any behaviour which the well spouse found unsettling could be attributed to the disease. For example, Mr. Jones retrospectively blamed the disease process on marital problems dating back more than twenty years.

> Now, that may have been an indication of her basic personality, I don't know..uh, on the other hand, it [referencing wife's decision to separate] happened a number of times after that and I think once again, especially towards the end because it was only a matter of being away a couple of days and she would, everything would be all over and she'd be great..I think it was a matter of perhaps her mentality getting at

her to the point where, where she was getting frustrated you know, took it out on me. (Mr. Jones)

I began to interpret the `labeling process' as a sign of a changing relationship between the participant and their partner. Specifically, in order to redefine one's role in relation to one's partner, the partner's symptoms had to be recognized as outside of the normative expectations of both the marital relationship and the aging process; the ill partner's behaviour had to be redefined as extraordinary. It was only when this `step back' was taken that the participants began to identify themselves as `caregiver' in a more socially constructed sense. In other words, recognizing and accepting that `something was wrong' exposed a previously hidden space for the well partner to develop a sense of one's self in relation to one's partner that transcended the relationship; this sense of self could be located outside of the personal relationship, within a more public setting. This then was the first step in moving the location of the caring activities to a more visible, public arena.

However, labeling of the problems was neither fixed nor did it proceed in an systematic fashion. Although there was a tendency for many of the participants to hold relatively stable understandings of their partner's problems, several participants demonstrated that even during the course of our conversation there could be some movement in their perception. Additionally, although it seemed that the longer one's partner was obviously ill the easier it became to label the problems as disease related, length of illness was not necessarily a reliable `predictor' of participants' interpretation. Rather some of the participants seemed to move quite quickly to an acceptance of the partner's behaviour as

illness-based; these participants all held strong positions outside of the marital relationship prior to the onset of their partner's symptoms which suggests the importance of this alternative positioning for sense-making.

A clue that participants were shifting positions was in their references to their partner. The well partner talked about his or her partner in a different way. Specifically, there was a sense of the well partner `othering' their ill partner. By this I mean that a psychological boundary was created between `I' as the subject and `him' or `her' as the object of attention. The ill partner was relocated into a context outside of the marital relationship that was being observed as opposed to experienced by the well spouse. For example, the ill partner would be referenced with more neutral terms such as `the patient' or, in recognition of their inclusion in the bounded group of dementia victims, as a `they'. As an illustration, referencing his wife's incontinence, Mr. Lowe comments:

> well with mental problems they all have it eventually. It's not unique at all. Because they go back to two years of age and that's all there is to it. Just like a baby. (Mr. Lowe)

Interestingly, although this positioning was relied upon particularly to explain problematic behaviours, most of the participants were acutely sensitive to other people `depersonalizing' their partner. For example, Mr. Lowe followed his previous comment by recognizing the uniqueness of individual's suffering from a dementia.

> I don't think anybody fits into the same slot...I'm talking about caregivers and patients, whatever you want to call them. I don't think any of them all fit, you just

can't put them into slots. They're not all the same at all. They're all a little bit different. (Mr. Lowe)

On a more personal level, Mr. Archer referenced his anger when others talked `over my wife as if she wasn't there' and Mrs. Ford quite consciously moved back and forth between talking to, and talking about, her husband. It seemed that while this distancing was an important step within the personal relationship, when dealing with the public the relational connection and the ill partner's personhood were often strongly affirmed. This begins to suggest some of the contradictions inherent in redefining one's relationship with one's partner.

Externalizing the issues through the process of medicalizing rather than utilizing other possibilities - such as attributing the behaviour to the stars - had a distinct advantage. Specifically, this explanation facilitated the adoption of a socially recognized and valued story-line for sense-making; participants could invoke a medical discourse for telling their own story. A new language which transcended the private language of familism was introduced.

For example, there were several `signifiers' which seemed to surface when the well partner was shifting positions. Most obviously, participants began to talk about `the disease'; it took on an entity of its own; "I realized it was not my husband, it was the disease" notes Mrs. Ford. Obtaining a diagnosis facilitated the development of this alternative language. Several participant's identified the importance of obtaining a diagnosis as early in the process as possible. These are the "words of wisdom" offered by Mr. Lawson regarding what he would like to tell someone in a similar situation:

> Tell them? I'd tell them to get help quicker than I did. Try to get a firm fix on just exactly what was the problem. To get the diagnosis and to get the medical help that could be of assistance. Before, I went through a lot that I should never have gone through I think...(Mr. Lawson)

Both the diagnostic process and professional attitudes seemed to conspire to make this process as difficult as possible. Dementia is a complicated disease to diagnose and the frustration associated with lengthy, inconclusive diagnostic procedures was raised by most of the participants. This already daunting process was made worse for a number of participants who voiced anger at having concerns initially "brushed off" by professionals due to both ignorance on normal aging issues and disinterest in the aging. For example, Mr. Lawson followed his above noted words of wisdom by detailing his difficulty in obtaining a diagnosis:

> I don't know, I don't know whether I put too much weight on our family doctor and as I said before with great respect, he's just inclined to be, if he can't put a band-aid on it or give you a pill or a prescription or if he can't cure what you've got, the geriatric side is sort of a lesser interest. He's more inclined to say well, you know "go to [some place else] you know, they're set up for it. Which is true and I can understand how he would feel...Our own family doctor who we had for years, he was a , he was a friend, he would go to any lengths... (Mr. Lawson)

Moreover, although a diagnosis was important, in and of itself the diagnosis was

neither absolutely essential nor necessarily sufficient for insuring that participants viewed their partner's problems from this perspective. This is because the intellectually `known' and the embodied perception were not necessarily aligned. Both Mr. Malloy and Mrs. Cook drew this to my attention. Although rationally they attributed the problems to a disease process both also inserted alternative subjective understanding into the issues: Mr. Malloy normalized his wife's deterioration as a sign of aging or their lengthy relationship and Mrs. Cook internalized problems as a sign that there was something wrong with her. Other participants also demonstrated this flexibility in interpretation despite the diagnosis. Conversely, three of the participants - Mr. Lawson, Mr. Green and Mrs. Macneil - attributed their spouses' problems to medical causes even without a definitive diagnosis.

In addition to the diagnosis, those participants who did begin to position their caring activities within a more public context identified the importance of obtaining information. While several participants identified positive assistance in this area, most described the frustrating process of having only themselves to rely on for obtaining answers. Concerns included that professionals, usually physicians, were too busy to offer explanations and that when explanations were forthcoming, technical language was used that was virtually incomprehensible to the participants.

Obtaining information seemed to have two important functions in precipitating a shift from the private location of caring to the public. First, as noted it gave the well partner a language for talking about the situation that was outside of traditional `relational' talk. Second, it allowed the well partner to become a `knower' in the situation.

A third way that participants seemed to demonstrate a shift along the continuum of

locating their caring activities was in their affiliation with other caregivers. Among the participants there seemed to be contrasting perceptions regarding whether one was experiencing a unique experience or saw similarities with the experiences of other caregivers. For example, Mrs. Cook generally viewed herself as `different than' other caregivers. In contrast, other participants began to reference an "us" or "we" when talking about other `caregivers', identified the commonalities in their situations with that of other `caregivers', and used the label `caregiver' to self-describe. Attaining a sense of belonging within this `collective', or `community', seemed to be important for broadening one's interpretation of one's role.

The transition from primarily `spouse' to `caregiver' seemed to occur gradually in a non-linear process and was certainly not fixed. Moreover, it was not a transition made by all of the participants. Rather, those participants who could be positioned as a socially constructed `caregiver' seemed to be those who were the most socially visible or powerful prior to their partner's illness. For example, except for Mr. Cashin, the eldest and longest retired participant in this study, all of the other men at least briefly positioned their caregiving activities within a more social realm. However, only two of the women consistently used this alternative story line to make sense of their experience. Both of these women had worked outside the home: Mrs. Ford, as a teacher had had her caregiving efforts economically validated and had seen her mother earn a living through caregiving activities; Mrs. Deboni's primary social network stemmed from her involvement in paid employment outside of the home. This finding would be consistent with other research which demonstrates that it is those who are relatively less oppressed and disadvantaged who will

first voice claims for change (Aronson, 1988). It introduces the significance that social positioning will play in relocating caring activities.

In summary then, although all of the participants initiated their understanding of their caring activities vis-a-vis their partner within the story-line that one's caring activity is a natural extension of the marital relationship, several of the participants began to broaden this conceptualization. Reframing their situation using language adapted from a medical discourse promoted an alternative discourse on caring to emerge which repositioned the well partner's activities within a more public sphere. This story line constructed `caregiver' as something different than spouse.

The positioning of caregiver in a more public realm had important implications for making sense of one's experience and consequently, in assigning meaning to the use of services. Specifically, positioned within this discourse service use could be seen as a `right'. First, the `work' that one was doing could be recognized and assigned value. For example, in their personal narratives both Mr. Archer and Mrs. Ford clearly situated their actions as saving the government enormous amounts of money. Similarly, Mrs. Deboni recognized that caring for her husband was in both her husband's and the government's best interest.

> ...I support a lot of home care service. If you can give a little bit more to the family to support, those people [referencing her ill husband] would be looked after properly. Of course the government gonna give less because if I give [my husband] away [to a care facility] I have to pay what I have to pay and then the government has to pay the rest. But it costs four times, three times more. In this way, [providing home care services] would be a little cheaper for them, if the family be

encouraged from the government the patient will be looked after a little bit better. There will be more good care...To keep my husband home I save a lot of money, if I give him away outside it costs more money. (Mrs. Deboni)

The personal expertise required to carry out the caregiving responsibilities was identified. "I've become the expert" notes Mr. Archer; "I am a professional" Mrs. Ford makes clear. Similarly, although she continually asserts that she is "learning, always learning" Mrs. Deboni recognizes her expertise as indisputable.

I am the one. My family doctor says "you have to tell me, and then I could do something for you". Because I've become a doctor to [my husband], you know...The doctor said "I depend on you to tell me how things are going". (Mrs. Deboni)

She uses the proverbial "we" to talk about determining appropriate medication dosages for her husband, counters the hospital staff's attempt to normalize her husband's screaming, and describes the process she undertakes to determine the cause of her husband's irritating rash. Throughout her personal story she clearly asserts her sense of authority and unquestioned competence. She will work in co-operation with the family physician, but when push comes to shove she demonstrates her intention to retain control.

I said "Dr. Tomm, [my husband] is very ill, I need your help, the hospital threw him out twice, what [should] I do?" Oh, he says "Mrs. Deboni, tomorrow's Tuesday, I'll come see him". Then I get very mad. I say "If you guys don't move, [my husband] is very sick, I [will] call the police." "You go that far?" Because my family doctor know, I am too particular for him....So right away he phoned the

hospital, they arranged that I can be there in a few hours, whatever. (Mrs. Deboni)

Once visible, the work involved in caregiving could be more accurately calculated. As highlighted by Mrs. Ford's previous comparison of her work week to that expected of a nurse, normative standards could be applied which sanctioned the need for support.

> ...you can't do things alone. You need people to help you. I mean, I did a lot of things by myself, but in the mean time, people friends, helped me to find this way, the way I did it you know. (Mrs. Deboni)

The recognition that there had to be limits could be voiced.

> I think it's very, they [the government] are cutting back on the, you know, we're not, they're not spending money on improving the facilities, they're not putting in more facilities for people to live in. And they're saying well, we've got to send out more health nurses and somebody to wash the dishes or something like that..if they can pay for it why they'll pay for it, and you know, keep them in the home. I couldn't agree more but the time comes when there should be facilities and there's no point in having people traipsing in and out of this house. Let me have a break after awhile. Let me spend the last couple of years of my life..There has got to be limits! (Mr. Lowe)

In other words, there was a sense of entitlement to assistance based on the recognition that one was providing a valuable contribution to society which exceeded what could reasonably be expected of one person. Of all of the story lines available for

constructing meaning associated with service use, this particular story was the most conducive to actual service use.

However, it was not entirely without contradictions. Specifically, although this position spotlighted the well partner's public contributions, the risk arose of being seen as selfish and lacking in a social conscience. Personal needs had to be balanced against the more global good. For this reason several participants argued persuasively at one point for `government' to provide recognition of their efforts - preferably in the form of financial remuneration and tax breaks - and yet could not take a firm stance on personal rights to costless respite services. In the following passage, Mr. Jones seems to move back and forth between anger and altruism.

> ...doctors have..uh, and this applies to heart specialist since I have seen two of them in particular - the one I have now...sometimes he'll give me some extra time but I know that if I take extra time over fifteen minutes then somebody else is going to be waiting you know, because it's the way that the thing is done. **And I'm not so sure that that's as good as it could be but...**[voice fades off - then picks back up] Now there's a possibility that [my wife] could go into ...a thing called a cognitive care unit...which would be ideal...So, a couple of doctors came around and saw her two weeks ago, assessed the whole thing, fortunately uh, she was in such a mood that she amply demonstrated exactly what her problems was so...they put this down and said "okay, we'll take her...". Doctor called me back..."well we thought we'd get her in for two weeks but beds have been cut back...And so the chances of uh - beds have been cut way back, chances of getting her in in the reasonably near future are now

pretty slim". You know, which, it's a general, it's the general downsizing or whatever of the health system that has been reflected right into the system, or the method of care in itself. **But I can't say that I'm against that because I don't know how we possibly can finance the type of health care that we have now.** (Mr. Jones - emphasis mine)

In summary then, the following points are important. First, although the prevailing discourse on caring structures it within the private realm, participants' stories revealed the availability of another story line which allowed caring activities to be positioned within a more public sphere. Second, using this alternative story line, caregiving activities attained a status and visibility lacking in the former story-line. This story-line provided a language for sense-making which fostered a sense of entitlement to support services.

So why were so few of the participants actually utilizing support services? Recognizably, this alternative story-line offered an underlying set of assumptions and beliefs that conflicted with the previous story-line which positioned the well partner's activities as an extension of the marital relationship. The well partner could conceivably be forced into unwanted choices. Moreover, unquestionably the first story-line was the more powerful. But how did it maintain this powerful position? Why was it so difficult to `restory' one's experience in a way that facilitated the use of services?

Producing the Dominant Discourse on Caring

When participants spoke from the position of socially constructed `caregiver', I

became aware of the rhetoric underlying the current provision of formal support service. Specifically, the participants' personal stories made visible practices which worked to maintain the prevailing discourse of caring as a private activity. I identified four particular themes regarding how services were offered which discouraged, rather than encouraged, the use of services. These consisted of challenging expertise, communicating disentitlement, disregarding relationships, and invading personal privacy. The following section will develop each of these themes.

A cautionary note is required before proceeding. Specifically, I want to make clear that not all comments related to service use were negative. Rather, what would be more accurate is that many participants could identify individual service providers whom they had found to be very supportive and helpful. In fact, when talking about individuals there was a tendency for participants to feel guilty about saying anything negative at all lest they be seen as `complainers'.

Challenging Expertise

Recognizing their contributions, several of the participants voiced the expectation that their relationship with service providers should be collaborative. That this collaboration was not in fact happening was initially highlighted by Mrs. Ford and confirmed repeatedly by other participants. Several talked about feeling "patronized", "invisible" and discounted. For example, Mrs. Deboni relives her anger at the assumptions being made by her husband's hospital care team that they knew what was best for her. Asked if she felt they were trying to remove decision-making from her regarding her husband's care, she responds

vehemently:

> Yes! Because the trouble is... maybe my English, the way I was looking tired...they think they could use me, they could make me do what they want....Say, maybe she's something we can you know, make them do what we want...And I said - then they want to keep me here and talk and talk. I says "you know, if the government stopped so many people sitting here and doing nothing, maybe they can give a little bit more service to people that need it" and I got up and left. I was fed up with them by then, that's it..."It's good for you?" [mimicking] How do you know it's good for me? Are you me? Is that your husband? (Mrs. Deboni)

Similarly, Mr. Lowe clearly felt his expertise and knowledge were being undermined when he noted that "the government doesn't give people any marks for intelligence, that they know best". Later he highlighted how new arrangements for accessing placement effectively undermined his control:

> The government has decided that there's going to be four zones here and everybody goes into a central registry and you're in zone two. They will tell you where, when the time comes, where she will go...we won't have too much to do [with it]. I've looked at a lot of places, not a lot but a few, and I know the ones I would like when the time came that she should go into, but I don't know whether I'll get that choice. (Mr. Lowe)

Most were quite sensitive to the undermining of their expertise.

> And I've had some nurses thinking that they know more than I do - but they don't know my husband!...it would help a lot if the medical professionals, starting with the doctors, and the people who work with us, didn't consider us inferior (Mrs. Ford)

Several points are important here. First, participants expected recognition to be accorded to their expertise, which was grounded in their intimate connection with their partner; *they* were the experts in understanding *their* partner's needs. However, it was often not the perception of the participants that this in fact happened. Rather, involving professionals in the care of their partner seemed to precipitate power struggles which left the well partner feeling undermined.

An antagonistic relationship with professionals was often, although not always, assumed. This perception of constant battling with formal support providers did have some positive repercussions. Specifically, several of the women indicated that as a result of their experiences with the formal support system they had become "stronger" and much more able to speak up for themselves. For example, Mrs. Macneil felt she had proved herself as a "survivor"; she didn't use to speak up for herself but after dealing with the hospital related to her husband's illness she had "learned her lesson". Mrs. Deboni described herself as

> ...stronger. I'm not the person I used to be...You have to change. If you don't fight for yourself people use you. They don't know your life, they make you do things wrong. (Mrs. Deboni)

and Mrs. White noted that:

> There use to be day when I would, was very reticent and I wouldn't say things, I

didn't want to make any waves, but not any more, I'm not like that. (Mrs. White)

Clearly, even though each of the above participants had experienced positive relationships with some *individual* service providers they viewed the `system' as adversarial. This was a common perception. It meant that participants had to be prepared to aggressively assert their needs or risk being trod upon.

Communicating Disentitlement

Almost all of the participants raised financial issues associated with the use of formal support services (and especially placement). In fact, despite the relative financial security of all of the participants - all could be considered to be of `middle class' socioeconomic status - several of the participants cited the cost of services as the reason for refusing to accept assistance. For example, Mr. Cashin notes that:

> ...they [the service provider] wanted ten dollars an hour and they did two shifts, one for night and one for day. That's two hundred and forty dollars a day. And I said no way can I afford that kind of thing at all. It's just out of the question. I said I know the price of a dollar and I said that's too much for me. So I just refused to accept it... (Mr. Cashin)

Similarly, referencing the possibility of obtaining regular support, Mr. Lawson notes that:

> it would be really uh..difficult I think to sort of meet a monthly bill of that nature from the available cash flow. And I said to her, [wife] you know, the last thing in

the world I want to do is to have to sell my house to support this - because I've heard so many horror stories (Mr. Lawson)

Although he had earlier identified the positive benefits of using the homesupport services, Mr. Lawson eventually resigned his part-time employment opportunities because he found the cost of the respite prohibitive; he felt he was working only to pay for this respite.

Positioned within the discourse of individualism and familialism, participants were quick to assert that they did not expect to be supported by the government. However, when positioned within the alternative discourse which located the public value of the caregiving activities, a different interpretation was possible. Here, it seemed to be more than mere affordability that created the anger around paying for services. Rather, several of the participants referenced the principles associated with paying for support. As made explicit by Mr. Archer, the requirement that one pay for respite services penalized the caregiver for requiring time away from caregiving responsibilities. From this position, the underlying message associated with paying for services becomes clearly visible. Specifically, questions are raised regarding the well spouses personal right to relief; the expectations of the `selfless' caregiver are implicitly supported.

Other practices reinforced perceptions of disentitlement. In principle, almost all of the participants indicated that support services were necessary and had the potential to be useful. Even Mr. Lawson, who repeatedly affirmed that he and his wife were "just private people" who "just want to be left alone" identified personal limitation in meeting his wife's

needs and suggested that having others assist would be useful.

> I certainly don't feel that I'm fulfilling her needs in that sense and I don't feel I can because I just um...there's nothing I can talk about that will last more than a minute....[But] if there's company in the house, or if there's somebody she can talk to other than myself, it seems to develop a better relationship, a better reaction, a better day. (Mr. Lawson)

In particular, at least at an abstract level, everyone spoke wistfully of the desire for respite.

However, on a practical level, most participants recognized the formal support network as dismally inadequate.

> ...oh, the government and a few others simply haven't any comprehension of what it really is, what it's like, They haven't' the foggiest idea... You know, they don't seem to want to have respite so people have a decent break. They say "oh well, people should stay in their homes". But they seem to have completely ignored the fact that it isn't just one person, it's two people. And um , the caregiver uh, in some ways they're just shooting them down. Not giving them a break at all...they say "oh well, we'll send somebody in with meals on wheels". They don't want meals on wheels! [voice becomes louder] Nothing to do with it. This is not a ...meals on wheels situation - it's a **24 hour** situation. (Mr. Lowe)

> [the homemaking services are] working out alright but...that's not the answer. There's 24 hours in a day, going around the clock and that's three hours... I had a mess here the other night in the bathroom...(Mr. Cashin)

> ...it's a lot of work for me...and I hope God gives more help to keep going with this...I wish I could find a little bit more help, but there's nothing more you know. I find it very hard, the night. I ask, I ask all over but not, they say no, no, no, so what can I do?... I hope some day this home care service could become a little bit more flexible to give a little bit more help for the family. (Mrs. Deboni)

In other words, almost everyone identified the gap between what was available and what was actually required.

Further to this, several of the participants voiced anger at the assumed dichotomy between caring for their partner at home and placement. Mr. Lowe became notably more animated as he proclaimed:

> I think the thing that annoys me right now is the government, they're not having more beds. They should be building more buildings for people to go to when the time comes. Um...they should be spending money on that instead of yapping about - and I'll use the word yapping because that's how disgusted I feel- they talk about more homecare, keeping people in their homes. People are going to keep them in their own homes, if they have any love or affection, they're going to keep them at home anyway. But when the time has come that they've got to go, then there should be decent facilities...If they [family] can do it they're gonna do it, in my opinion. (Mr. Lowe)

Moreover, an ultimate impact of fiscal restraints, cut backs and inadequate services

was to open up the likelihood that participants could feel guilty about being a burden for using these services.

> ...they [hospital staff] do what they can. They're short staffed, okay? [My husband] takes two hours to feed him, where are they going to find the help. (Mrs. Deboni)

> she [the nurse] is pretty good, you know. But I hate to bother - you can't get her direct, you've got to go through the secretary and if she's busy, I call and call and call and then she can't get through to the secretary. (Mr. Cashin)

The underlying assumption then, seems to hint that participant's are not entitled to adequate support and should be grateful for whatever they can get. This supports the story line that the caring activities are a private responsibility and implies a public bestowment of favour. This was made quite explicit by Mrs. Ford who recognized that her "demands" for responsible service had earned her a designation as "B.I.T.C.H".

Disregarding the Relationship

Although it was the relationship with their partner which both grounded their assumption of the caregiving activities and gave them an edge in providing care, many of the participants described the difficulties that they encountered when trying to insure a trusting relationship with potential service providers. For example,

> what I wanted was to see the girls, I wanted to know who it was going to be. And they said well, they didn't have that policy. I said well, that's unfortunate because

I'm not going to leave my husband with somebody that I don't know anything about or have never seen. So they said, well, okay, we've never done it but we'll send her for an hour. But I was charged for that too. (Mrs. Knight)

Similarly, several other participants indicated that they would not leave their partner alone unless they found somebody who could be trusted. They wanted to know who the person coming in would be and assure themselves that this person was competent and willing to meet the needs of their partner. Not unexpectedly, this was identified as a particular priority given that their partner could not personally communicate his or her needs - the well spouse needed to personally guarantee their partner's well-being and be in a position to communicate for their ill partner. All of the participants described both perceived and experienced obstacles to establishing a level of comfort with a home-helper.

Unless a trusting relationship was established with the support worker these individuals were seen as "strangers".

I'd rather not have strangers, I can't call them intruders but they would be. [However] If I knew somebody, I would be delighted to have them come and help to do things, and mainly to, it's the old, old idea of respite - to get a break. (Mr. Lowe)

I just don't like it, you don't know who you're going to get. I shouldn't say that...It's the truth. You know what I mean...I'm always very cautious..Some people are..extremely nosy and when I go into a home I don't go in to see what they have, I go in to visit them right? But you'll get some people and they'll ransack everything.

> When you don't know who they are or, you know what I mean, even if people say well their a hundred percent, just the same...And then there's another thing maybe they wouldn't..[my husband] wouldn't be pleased with them or they wouldn't be pleased with [him]. You don't know! You know, personalities are personalities....You might think I'm funny like that. I like to pick..because I pretty well know who [my husband] would like after being married for the 48th year. (Mrs. Macneil)

Furthermore, there was a question that the individuals were being adequately trained.

> well actually, the poor things, I think some of those people just don't know the difference. And if you're going to start training them, it's easier for yourself to do it. That's what I think. (Mrs. Macneil)

It is interesting that instead of the normality of their expectations being confirmed, it became easy to individualize the issue. For example, referring to the need to have a trusting relationship with anybody with whom she would be leaving her husband, Mrs. Macneil describes that as "the whole thing". She goes on to suggest that:

> I suppose people see that as kind of picky of me, but no, see, we never had to do this before. We never had to do this before...To, to get to have somebody you know, for either one of us...it's kind of tough [sighs] ... You know, you don't, you don't, you're not going to go out unless you get someone that you rely on, you are not going to go out. (Mrs. Macneil)

She repeatedly individualizes this as her problem: "That's my, I suppose, that's my weakness, I worry." "you must think I'm being picky"; "you might think I'm funny like that" and as stated above "I suppose people see that as kind of picky of me".

Ultimately, for help to be successful it seems that the barrier to using a stranger had to be overcome. People had different ways of doing this. What all seemed to have in common was a thrust toward personalizing the connection. In particular, the importance of a personal, informal connection to the person, regardless of how remote, seemed to facilitate the involvement of someone else in the care of one's partner. For example, Mrs. Macneil obtained a home support worker through a reference from a friend. "And we called her and she wasn't working at the time so...." What came through most strongly in Mrs. Macneil's story was the importance of the personal relationship with this person.

> Jan [homesupport worker] the little nurse friend of ours, she's coming down [tomorrow] gosh yes, I couldn't go without her...I feel so safe when Jan's with [my husband]...She's really something else. She's a lot of fun. She'll be good to [my husband], and she should know what to do.... Oh Jan, she's a real friend....She [isn't] here to work, she [is] just here to sit with him (Mrs. Macneil)

Similarly, Mr. Cashin clearly associated his meal delivery service not with an organization but rather with his `neighbour' who lived up the street. It was through this neighbourly connection that he began receiving the service.

> Well, it was, the lady the second door away from here, she volunteers, she goes brings people the meals. She goes and delivers them I should say, and the odd time

she, a lot of them are missed you see. Yesterday - and I felt awful you know, even though I had two sticks across the veranda..but you can't get up - but, and I was trying to get the car started and she came earlier about quarter after eleven, she says "I was here and I couldn't get in" Well, my wife couldn't hear her. See. She didn't get in. And here it was, pretty near 1:00. And they phoned from the Meals on Wheels and she was down there, I guess she left everybody, her routine was done but she had ours and she wanted to know if we were at home. I said "that's awful, to think the my neighbour couldn't get in". (Mr. Cashin)

Mr. Lowe also objected to having a stranger in his house. I was surprised to discover during the following interview that he had arranged for someone who he did no know to come in to look after his wife.

Now tomorrow a lady is coming here and she will be spending from nine to four here. And we're going to try that and see how that works... It's a private lady that I learned about. She's from Halifax and come up to Toronto. [I found her] through my daughter..She just said well, I know this lady, it's through another person, you might want to interview her and etcetera... [The difference between using her as opposed to someone from the homesupport service is that] well, I've interviewed this person, and I think she'll be fine and I think she may be what would be nice for [my wife] (Mr. Lowe)

This individual is perceived as clearly different from an agency provided person. This is because: the introduction is initiated through his daughter (even though his daughter does

not personally know this person); he has some choice in selecting her because he is able to interview her; and finally because he interprets her involvement as "something she wants to do, that she would like to do" in contrast to the `financially motivated' formal support workers. What these three individual's highlighted was the importance of a personal connection, regardless of how remote, and the opportunity to reframe the helper's role using a more relational language.

Formal support services enter into the well partner's experience with a deck of cards stacked against them. Almost all of the story-line's available to the well partner for making sense of his or her experience included negative connotations associated with service use. The importance of relationships ground several of these story-lines; for example caring as an extension of the marital relationship is both founded in and maintained by assumptions and beliefs about the relational connection and obligations between the two spouses. Participant's described formal support practices that actively conflicted with these story-lines and therefore served to minimize the use of services.

Invading Personal Privacy

Retaining a sense of personal privacy was clearly endangered by the use of formal support services. Participants identified three ways in particular that this happened. First, as noted above, issues around having strangers in their home were raised by most of the respondents. Referencing a conversation with the service coordinator that he had while exploring the possibility of in home support Mr. Cashin notes that:

Well, if you have somebody coming in, I asked them if it would be a different

person all the time. "Well, it could be". And I said "Well, what if I am not in when they come and she [his wife] can't hear very well?" "I guess they wouldn't get in. They might want a key". Well, I don't know how reliable they are. And if you take the key and have others made and uh, they could be in this house - not that there's anything that valuable in it or anything , but I wouldn't want to have my house robbed or ransacked.

You know it's the old story, are you comfortable with having a stranger in your house? Well? I'm just saying, are you comfortable with having another, somebody you don't know in your home? (Mr. Lowe)

Second, related to issues cited above regarding cost, in order to avoid paying for services participants had to be willing to provide considerable financial information. Mr. Cashin gives his response to this practice:

I just said "no". I said, "that's my own business" I said "nobody'll ever find out, good or bad, how much money I have or haven't got. It's my own business"

Referencing the expense of home support services he adds that "I said `if that's the kind of help I said, that's not helping me, that's hindering me too much"

A third way that the use of formal support services invaded the participants sense of personal privacy related to the loss of control they experienced over their own schedules.

you'd be driving the car, you go, well, it's 2:00. I better get the book out give her a drink and give her a pill and all this kind of thing. It's so regimented (Mr. Lowe)

When it talked about [the day centre program] uh, the woman said up there that you could try for a week or something with her or certain things I think I mentioned to you that they expect you to do kind of a regimented approach or you get assigned or you get this... (Mr. Lawson)

Similarly, although he described the help he was obtaining from the homesupport worker as helpful because it allowed him to go out a get a "few things done and I don't have to worry about how she's getting along alone", Mr. Cashin responded quite definitively that he would not be interested in more of this service. He provided the following rationale for his refusal:

You know, we have meals on wheels and you have to be here, or they don't leave them. I said "why not just leave them if I'm not, and somebody knocks on the door, leave them in the, in my milk box.?" They're not allowed to. Well, why not? but then, I can, I can see their point. Maybe there'd be somebody sneaking around if they got to know the meals were put there they'd swipe them on you. (Mr. Cashin)

Mrs. Macneil was frustrated in her attempt to arrange monthly homesupport:

The only time I would want someone for an extended length of time..see I have, I've got everything down to a system. I have to have. If I don't I do this on this day and that on that other day. and this on some other place on that other day. If I would have someone that could come in with [my husband] - maybe I'm too fussy - on the 28th of each month, that's when I need someone....That's all I wanted. And I, I put the

time on as three hours... - of course I'd be jumping and running for three hours, but three hours, that's all I wanted for my running was three hours on the 28th because then I could get, the cheques would come on the 26th and 27th...But, you know, we [referencing the home support agency] didn't agree on the dates at all...She says the 28th can fall on a Sunday, then you're out of luck. Then you carry through the 28th, the 29th, 30th and 31st and to the first until the first day possibly of the month. I don't want that. Our supplies are booked. I have everything scheduled and I'm not going to be behind on it and if we need milk today, four days time is no good to look for it is it?...So we'll get, we'll get somebody ourselves. (Mrs. Macneil)

Several of the men mentioned the disruption to their routines using formal support services entailed.

I do laundry four to five times a week, little bits and things. What the heck good is it to have somebody come in and do my laundry on Friday or something...If something goes wrong and I have to wash something up, then I'll wash it up then. Not throw it in a smelly old bag until Friday. But they don't understand that. (Mr. Lowe)

He describes it as "absolutely" easier to handle things himself rather that have somebody else come in.

These examples illustrated to me the expectation that in order to take advantage of formal support services, there was an assumption that one would structure one's private life around the use of the public services; once again this gave the underlying message that the

participants did not have any `rights' to services but rather services could be positioned as doing them a favour. Moreover, the reality was that even in restructuring their time the services being provided were burdensome and could create work rather than easing the burden.

CONCLUSION

In this section I have attempted to explicate the importance of particular discourses for assigning meaning to the use of formal support services. Specifically, I have conceptualized my understanding by identifying two intersecting `sites' or `axis' that are important for constituting the caring relationship. Within each of these two sites, I have distinguished competing positions; these positions have discourses, or story-lines, associated with them which influence the personal meaning associated with formal services.

The first site locates responsibility for the caring activities as falling somewhere between a private/public responsibility. Associated with each of these two end-points is a set of beliefs and assumptions which make up a `story-line' about that particular location. These two story-lines provide competing frameworks for making sense of one's personal actions and responsibilities vis-a-vis one's partner. At the one pole a story-line is available that positions caring activities solely as an extension of the marital relationship, and hence private. The opposite pole is made accessible by a story-line that broadens responsibility and recognizes the caring activities as a social contribution. Depending upon the individual's location on this continuum these story-lines will exert differing amounts of influence on the individual's personal sense-making. I have tried to demonstrate that the

story-lines used to locate one's caring activities have strong implications for the meaning associated with service use.

The second site, which intersects with the first, locates one's psychological orientation on a continuum between evaluating one's sense of self according to standards of independence or relational connection. At one end, a story-line is fostered that promotes the importance of being independent, autonomous and self-controlled while at the opposite endpoint, the story-line posits a sense of self that is judged by the quality and connection of one's relational attachments. The story-lines associated with these two theoretical endpoints provide two more competing frameworks with which to make sense of one's personal experience and which also implicate the interpretation of service use.

Practically, this means that individuals will potentially be `hearing' simultaneously four different story-lines for sense-making. However, some story-lines will be louder than others depending upon the individual's location within the quadrant created by the two intersecting `sites'; for example when understanding of the caring activities is located closer to the `private' endpoint, the story-line associated with this endpoint will undoubtedly be more powerful than the more distant story-line associated with locating caring activities as a public responsibility.

By making visible the story-lines that are used to make sense of the experience the possibility emerges for change.

> How we live our lives as conscious thinking subjects, and how we give meaning to the material social relations under which we live, and which structure our everyday lives, depends on the range and social power of existing discourses, our access to

> them and the political strength of the interests which they represent...at any given point of time, the individual is both the site for a range of possible forms of subjectivity and subjected to the regime of meaning of a particular discourse and enabled to act accordingly. (Weedon, 1987 p.26)

Using this `model' for understanding, the goal becomes to determine where an individual is positioned in the quadrant created by the two intersecting `sites' in order to assess which story-lines are most influential for assigning meaning to the use of formal service for that individual. By understanding this, service providers can begin to untangle and challenge the meanings that will be associated with service use by that individual. They can also, intentionally or unwittingly, promote some story-lines over others; for example participants used their experiences to critique the practices that produced the dominant discourse on caring as unhelpful.

The following chapter will examine some of the implications that this model for understanding service use has for practice.

CHAPTER 8

TOWARDS LESS OPPRESSIVE 'SUPPORT':

STRATEGIES FOR PRACTICE

This study has explored the interface between the experience of living with a memory-impaired partner and the use of formal support services. Specifically, the purpose of my study was to improve understanding regarding the formal support service needs of elderly spouses living with a partner who suffers from a dementia. Research has documented that these spouses are at high risk in the caregiving role, yet are the least likely of all caregivers' to utilize formal support service. To date, this low utilization of services by these individuals has been poorly understood despite concerns that without assistance, these spouses may jeopardize both their own health and well-being *and* the quality of care being provided to their partner. In order to begin addressing this gap, my study explored how the experience of living with a spouse who is mentally deteriorating interfaced with the meanings associated with formal support services.

The primary insight emerging from this study regards the importance of particular discourses for assigning meaning to the use of formal support services. Specifically, participants made visible that there were several story-lines which could be used to make sense of their experiences. Two specific areas, or sites, were identified which had particular relevance for making meaning about service use; one site was important for grounding one's understanding of the structure of caring, and the other provided a base for organizing one's psychological orientation. Within each of these sites opposing story lines were identified and participants could situate themselves (or be situated) on a continuum between the two poles

depending upon the influence that each story line exerted. In total, four possible story lines were identified and each of these story lines provided an underlying set of assumptions, beliefs and practices which impacted the meaning associated with the use of formal support services. What complicated the picture was that these stories lines could provide conflicting "interpretive repertoires" (Burman and Parker, 1993) for sense making so meanings associated with service use could be diverse and contradictory. In other words, the position from which a person was speaking in a particular moment provided the basis for that moment's meaning making; speaking from a different position could offer a different reading. This accounts for the inconsistent meanings associated with service use held by many of the participants.

In some ways this is a radical departure from the traditional ways in which service use has been examined to date. Specifically, service utilization studies have typically approached the issue from a more linear perspective which assumes a rational, fixed way of making meaning. For example, `need` as a predictor of service use has been conceptualized as an objective, static entity which simply requires 'teasing out' In contrast, I am suggesting that 'need' will vary depending upon the story-line in which one is positioned at a given moment. For example, positioned within the story-line of the independent self need may be defined around issues of being in control; in contrast when positioned within the story-line of the caring spouse, 'need' may centre around `keeping one's promise to one's spouse' (Ganzer and England, 1994) or preserving one's partner's personhood. Other studies have similarly assumed fixed, rational decision-making in examining the importance of personal values on decisions to use services (e.g.. King, Collins and Liken, 1995) and in

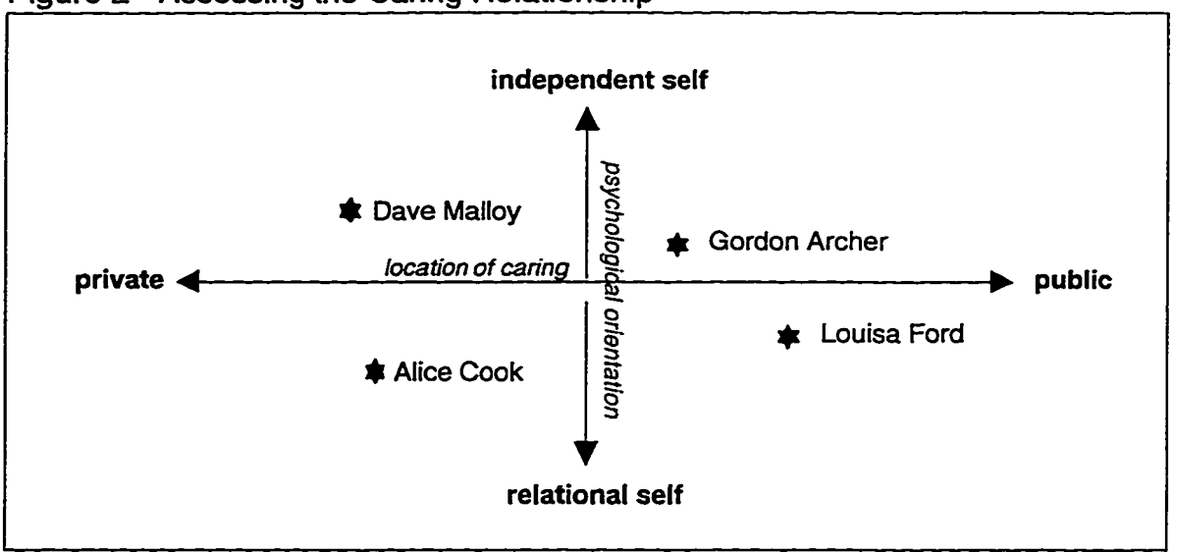
assuming the presence of "ultimate meaning" associated with service use (e.g.. Farran et al.,1991). My study would dispute these assumption suggesting instead that values and meaning will be ordered differently depending upon which story-line one is utilizing in that moment. It then becomes important to determine the story-lines that are available and influential for sense-making by each individual. Overall then, an important aspect of this research is that it renders problematic a simplistic understanding of the use of formal support services by spouses living with a memory impaired partner.

"So what?" you might ask. Why is this important and how can it be used? The remainder of this chapter will begin to address this question by exploring the implications of this research on Social Work practice and suggesting ideas for future research.

IMPLICATIONS

This study identifies the importance of assessing the influence of particular story-lines for positioning the well spouse's interpretation of the meanings associated with the use of formal support services. Figure 1 provides a useful tool for conceptually situating participants in relation to the two intersecting sites or axis. Specifically, although positioning did not remain fixed, with the participants in this study it was possible to begin to graphically locate the story-lines which were being used most readily for sense-making. For example, my assessment of where each of the four individuals presented in the case studies were positioned on this quadrant is illustrated in Figure 2.

Figure 2 - Assessing the Caring Relationship



Using this diagram, it can be seen that for Mrs. Cook, the story-lines which seemed to exert the most influence were those associated with locating caring as private responsibility and a psychological orientation that was relationally based. In contrast, Mrs. Ford imposed a public discourse on caring into her understanding of her activities but like Mrs. Cook was oriented toward experiencing her self in relation to an other. Mr. Malloy colored his perception of his activities as grounded in his marital relationship with a story-line which fostered the importance of individual autonomy and independence. Finally, Mr. Archer was positioned more evenly on the private/public continuum and expressed a strong belief in his sense of self as independent and autonomous (although the influence of the relational story-line is also present to a lesser extent).

Understanding the story-lines can provide insight regarding what some of the issues around using services may be and offer practical approaches for directing intervention. Some of these implications for intervention related to each of these story-lines will be

explored in the following sections. It is important to note that although I am examining these story lines as distinct entities, in reality they overlap and may exert different amounts of power at different times. Furthermore, actions which may be useful within one story-line have the potential to have a different, and perhaps contradictory meaning within another; this necessitates a constant balancing act. Finally, while I believe that there are some actions that we as Social Workers can be taking to provide better service, in no way am I offering a 'recipe' that guarantees that all spouses living with a memory impaired partner will, or should, utilize available services. This expectation would undermine the complexity of this issue and could be used to once again position the well spouse as problematic were he or she to continue to choose not to use services when the `fact` remains that this understanding remains partial and incomplete.

Caring as an extension of the marital relationship

This is the story-line associated with the location of caring as a private responsibility. The assumption within this story-line is that caring is a natural extension of the marital relationship. This means that there is little choice associated with the 'decision' to provide care to one's partner; rather it is an implicit part of the 'bargain' attributed to both love and obligation. It assumes that the well partner has the attributes and skill required to provide this care based upon the intimacy of the relationship. It also implicates that caring activities take place in private.

The influence of this story-line could be heard in all of the personal narratives told by the participants in this study. Furthermore, the importance of it for assigning meaning to

service use is supported by at least one other study. Specifically, in their study examining how values related to the use of services by caregivers, King et al. (1995) reported findings which support the importance of a dominant discourse on familism as private, self-sufficient and obligated to care. This story-line then provides a critical foundation for understanding service use.

In it's purest form, this story line positions the use of services only with pejorative connotations. Specifically, utilizing services means that one is not able to manage one's responsibilities as spouse and is therefore deficient; for example, in order to utilize services one must acknowledge that one is 'having problems'. This story line promotes the individualization of any difficulties related to meeting the demands of an ill spouse and discourages the use of services until the well spouse is so exhausted that his or her own health may be suffering. It raises questions about entitlement to services (Savishinsky, 1990) and promotes the pattern beginning to be observed in current research that service use is "too little, too late" (Cohen et al., 1993; also Gottlieb, 1996; Gwyther, 1994; Montgomery and Borgatta, 1989).

To challenge this location of caring, an essential Social Work task becomes to assist the well spouse to begin to articulate a new story line for making sense of his or her experience that positions difficulties as situational and not individual. Several strategies may assist with this task. These include: developing a reflexive practice which questions the underlying assumptions of 'caregiving'; 'medicalizing' the ill partner's behaviour; deconstructing the notion of care; and breaking the barriers of isolation.

These strategies will be explored as a means for promoting the questioning of the

story-line that caring as a 'natural' extension of the marital relationship requires the limitless hands-on provision of care. I recognize however the futility of promoting a different individual story-line when the societal story-line doesn't change. Therefore, developing services that foster a more public story line will be addressed later in the chapter.

Questioning Underlying Assumptions of Care

> Language seems almost magical. Only through its powers to name can we identify our experiences and our persons. There are no social structures that bear upon us beyond this linguistic order. All that exists is within it. If we want to change our lives, we need to change our patterns of discourse. (Gergen, 1992 p.141)

Naming is a powerful act (Brown, 1993; Aronson, 1988). Through the process of naming them, Social Worker can become aware of hidden assumptions and expectations that they have regarding how caring is structured within our society.

> ...when [social workers] are unaware of the embedded-ness of their views and how they participate in discursive practices, they are unlikely to be open to alternatives that are being obscured. (Hare-Mustin, 1994 p.33)

As long as caring for a memory impaired partner is unquestionably positioned within the discourse of a caring marital relationship, inherent contradictions in effectively utilizing supportive services can be expected. In order to overcome these difficulties, Social Workers need to begin to question assumptions embedded in the dominant discourse which currently structures caring. Through this process, they can begin to examine the ways that they

contribute to social control by "subtly holding clients in powerless positions and reinforcing identities ascribed to them by the dominant order" (Fook, 1993 p. 60).

Specifically, is it our expectation that because of a marital commitment to another individual, the well partner should be expected to quietly sacrifice his/her life when one partner becomes ill? This is currently the implicit expectation associated with dominant views on marriage. This assumption guarantees that individuals believing in this story-line about marriage will feel deficient, guilty and inadequate should the responsibilities of coping with an ill partner be beyond one's capability.

There is some recognition that there `should` be limits. For example, Directives from Health and Welfare Canada suggest that "at a certain point, family responsibility becomes society's responsibility, and caregivers need to be assured that they will not be expected to shoulder limitless burden" (Striking a Balance, 1988 p. 17). Social Workers need to examine their own attitudes and underlying assumptions to determine where that `limit' is. Repeated research findings which highlight the significance of caregiver health as the primary determinant of placement (e.g. Cohen et al., 1995) would suggest that the only legitimate exit from the responsibility of caring for one's partner is when one is visibly ill oneself. Is this really society's intention? Only by consciously naming our assumptions can we begin recognize the hidden impact that these assumptions have on our beliefs about what is acceptable.

If there is an inherent conviction that spouses *do* have the right to a life even after their partner may loose much of his/her ability then service use must be reframed as a right to these individual's. It is the responsibility of health professionals, including Social

Workers, to convey the recognition of that right through both policy and practice.

Moreover, is there a right not to be the primary caregiver? The current emphasis on 'supporting the caregiver' allows no recognition that it may not always be support - even practical support - that family members want. Alan Walker has argued for a charter that ensures carers `the right created by realistic alternative *not* to care for relatives, and if they do to be adequately rewarded" (quoted in Croft, 1986 p.28). Croft (1986) argues that policies are currently being conceived and implemented that do not offer carers a real choice as to whether they want to remain primary carers or not; services are to prop up the carers rather than to take the brunt of responsibility from them. Opie (1992b) describes this a the "misapprehension" prevalent in social policy assumptions which too easily reads the "fact of caring as synonymous with desire to care" (p. 53). At it's most obvious level then, this means that the assumption that all spouses are in fact in the best position to provide care requires conscious questioning. In my study, three husbands acknowledged some form of physical aggression against their ill wife and in a fourth case it was highly suspected although not confirmed. Of these individuals, at least two would have willingly relinquished their role as primary care provider to their spouse had there been a legitimate alternative. However, it also means recognizing that spouses who may have the requisite *skill* to care may in fact not *want* to provide instrumental care; women for example who have traditionally been assumed to possess `caring skills` should not be excluded from this consideration.

A first step then in undermining the story-line that caring is a natural extension of the marital relationship is to become consciously aware of it. This requires that Social Workers

begin to name the assumptions associated with this story-line and question the implications of these assumptions.

`Medicalizing' the Dementia

The ways in which participants 'named' their partner's behaviour and symptoms emerged as an important consideration in understanding the meaning associated with service use. Specifically, one's interpretation of the disease seemed to be related to how one positioned oneself in relation to one's partner. Some explanations, such as attributing behaviours to longstanding personality traits or normal aging, were less conducive to 'normalizing' the use of services than others. In particular, explanations which 'medicalized' one's partner's symptoms seemed to provide an alternative language for making sense of one's activities that facilitated the use of services; it made available a new story-line.

The importance of naming found in this study is consistent with the findings reported in other research exploring the experience of caregiving (e.g.. Askham, 1995; Bond, 1992; Savishinsky, 1990) and some research has concluded that it is particularly meaningful for spouses. For example, findings by Miller Glasser and Rubin (1992) indicate that spouses may be less likely than other carers to attribute symptoms to a disease process; they suggest that this can be explained by the familiarity of spouses with accommodating to situations defined as 'normal aging' which means that they will be less likely to notice the symptoms of a dementia. Pollitt, Anderson and O'Connor (1991) concluded that it was *the way* that spouses perceived their partners and their subjective experiences of caring that differentiated

spouses from other carers. They suggested that the way spouses perceived their partner's problems reflected their need to preserve the continuity of the marital relationship and that once the cognitive deterioration was medicalized these spouses no longer attempted to keep up the appearance that life was continuing in the same way as before; this positively impacted their willingness to utilize available formal support services. The importance of 'naming' the disease is identified as an important step in 'de-normalizing' the experience that may be particularly difficult for spouses.

A strategy then in assisting spouses to articulate a new story-line from which to position their activities would seemingly be to focus on explicating their partner's symptoms as extraordinary. This could be done by `medicalizing' them. Several steps for working toward this are identified.

First, the need for an accurate diagnosis was reaffirmed by this study. Specifically, many of the participants identified the importance of obtaining a diagnosis for helping them to depersonalize their partner's problematic behaviour; without it, it was particularly easy to normalize problematic behaviour as a symptom of aging or individual personality. The diagnosis provided a different language, the language of medicine, for talking about one's experience. This allowed the well spouse to reconstruct their position in relation to their partner.

This finding regarding the importance of a diagnosis is in contrast to some research which found a tendency for both physicians and caregivers to perceive a diagnosis as futile or having only negative implications.

Perhaps the most disturbing implication of our findings for practice is the lack of

> recognition by physicians and families of the importance of having a definitive diagnosis...Recognition of the discontinuity between accurate diagnosis and beneficial treatment strategies appears to create a `hopelessness' that underlies the diagnostic process. Physicians and families share the negative perceptions that learning how to distinguish dementia from normal aging means little since there is no available cure (Miller Glasser and Rubin, 1992 p.146)

This reluctance to name may help explain the frustration that many of the participants in this study identified with the diagnostic process. Several identified being confronted with disinterested and/or unknowledgeable professionals who did not take their concerns seriously. As well distress was acknowledged regarding their own lack of knowledge and understanding about diagnostic procedures. This appears to be an area for Social Work intervention. Specifically, Social Workers can help to demystify this process by providing information regarding assessment protocols. Additionally, they can validate the well spouses' expertise regarding their partner by recognizing the veracity of their claims that something is wrong and, where appropriate, advocating on their behalf for appropriate medical attention.

In addition to promoting the need for a diagnosis, Social Workers can insure that adequate and appropriate information regarding the disease process is accessible to the well partner. This was a gap identified by a number of participants. Specifically, several identified frustration at being given insufficient or overly medicalized information that they could not understand and others demonstrated to me a very poor comprehension of the

process. For those who did feel they had obtained some level of 'expertise', a haphazard process requiring considerable individual motivation was described. Contraindicating the lack of attention to this issues, obtaining appropriate knowledge seemed to have the potential to assist the well partner to fully comprehend the implications of a diagnosis. Furthermore, it provided the pre-requisite knowledge base for positioning one's activities within a more professional discourse; the well partner developed a sense of self as 'expert'.

An important function of the Social Work role then is to explore how the well partner is making sense of his or her partner's problems. This study suggests that until the ill partner's symptoms are interpreted as outside of `normal' expectations the story line most accessible to the well partner is one which privatizes their caring activities. Medicalizing the partner's symptoms has the potential to offer an alternative interpretation which can remove the guise of normality. This means that an appropriate focus of Social Work intervention may be to assist the well partner to begin to medicalize his or her partner's symptoms. This can be done by promoting the need for a medical assessment, facilitating the diagnostic process, determining the well partner's level of 'technical' understanding and insuring that individual need for information is met.

There are a recognized risks in medicalizing the issues however. First, there is risk that families, as consumers of services on behalf of impaired relatives, will be encouraged to seek only medical help (Gwyther, 1994). Second, this strategy encourages the depersonalization of the ill partner; this has potential implications for both the holistic, humane treatment of the ill partner and also conflicts with the assumptions and messages associated with the story-line which posits the importance of relationship. Finally, this

strategy preserves the status quo that the only acceptable exit from assuming private responsibility for caring activities is through medical problems.

Deconstructing the notion of care

A third focus that Social Workers can use to unsettle the assumptions related to the perception of caring as a natural extension of the marital relationship is to begin to deconstruct the notion of care. If family membership is defined by it's ability to care (Bould, 1993) than teasing out and pulling apart what this concept actually means would be important. This would require explicitly exploring the well partner's understanding of what it means to 'care'. One objective would be to begin to separate the dimensions of 'caring for' as a labour from 'caring about' as an emotion or expression of love (Baines et al., 1991; Fisher and Tronto,1990). Specifically, the possibility of continuing to care about one's partner despite relinquishing some aspects of providing the actual care can be addressed.

Additionally, Askam (1991) identifies the need to differentiate between 'care' and 'service use'. Suggesting that the two are often used interchangeably she provides four guidelines for distinguishing between the two. First, she notes that while care is a general term encompassing but not specifically defining any task or action needed to support or help another person, service refers to specific tasks or actions. Second, the person providing the care is in control in contrast to the service provider who is 'serving'. Third, care implies a notion of affectiveness rather than the affective neutrality implied by services. Finally, there is a concept of moral worth implied in the concept of care and carer but not in service providers (Askham, 1991 p. 141).

These distinctions might be usefully referenced by practitioners to assist in demarcating the responsibilities and roles of service providers and the well spouse. The benefit is that it enables the well spouse to retain his or her status as 'carer' while simultaneously relinquishing some aspects of the provision of care. The tension however, is that it fosters the concern identified by a number of the participants regarding the importance of intimacy for recognizing and responding to the ill partner's needs; the well spouse remains the only person who can truly respond to his or her partner's needs. This means that use of this distinction requires discrimination based on careful, individualized consideration.

Beginning to deconstruct the notion of care opens up the space to begin to attack the dichotomous segregation between 'caring' and 'placement' to develop a true 'continuum of care'. For example, for all of the participants in this study placement in a care facility invariably evoked the image of abandonment. Translated, this meant that unless providing hands-on care it was easy to discount the notion that one still cared. This overlap requires disentangling.

Breaking the Barriers of Isolation

A pervasive theme in both this research and other research on caregivers is a sense of intense isolation. Research suggests that the intensity of demand on carers, the loss of time to maintain friendships and interests and increasing exhaustion can contribute to the growth of mutual dependency and isolation (Opie, 1992b; Abel, 1991). All of the participants in this study referenced increasing isolation as a condition of their experience.

In addition to the discomfort that isolation causes, it also prohibits a redefinition of one's activities. Rossiter (1988) discussing the organization of mothering, identifies isolation as structuring sole care-taking.

> in isolation, the fluidity of identity is experienced as a loss of self...because the social situation in which one's identity is normally continuously re-constituted simply disappear... (Rossiter, 1988 p.244)

From this perspective isolation prevents an alternative story-line from emerging because there is no opportunity for new or different understandings to be raised or explored; meaning always emerges from social interaction (Deaux, 1991 p.78). The perception of one's activities will remain grounded in the private.

An important step then is to begin to attack the barriers of isolation in order to create the space to question. One means toward this is through the relationship between the Social Worker and the well spouse. The Social Worker can provide a valuable external source of recognition of the work that the well partner is doing and assist in renaming the experience. This relationship can provide a social context through which the well-partner can reconstitute his or her identity.

Second, the importance of connection with other caregivers was highlighted by several participants as critical; it helped them to realize that they were not alone and that the issues and problems they were dealing with were not individually owned but rather a shared experience and thus situational. This perception is support by Deux (1991) who suggests that the construction of a social identity involves at least three interrelated process: the self must be defined in terms of group membership; relevant information about group

characteristics must be acquired; and there must be a public proclamation of belonging to the group (Deux 1991 p.90). Aronson (1988) identifies the development of a collective, rather than an individualistic identity and awareness of strain, as key features of social change process (Aronson, 1988 p.239). In other words, encouraging the connection of the well partner with other caregivers in similar situations fosters a redefinition of one's activities that allows the caring activities to be structured using a more public story-line.

Traditionally, the primary way of fostering contact with other caregivers has been through the use of support groups. The difficulty with this approach is that it presupposes some degree of motivation to attend a group; specifically some recognition of the possibility of sameness/similarity with other caregivers is both a prerequisite *and* an outcome. Furthermore, the group has to be seen has having sufficient potential to warrant the probable amount of work and energy that it would take to get oneself to it; in other words even prior to attending it the potential rewards must be immediately visible. This has several implications for practice. First, although theoretically support groups may offer a valuable opportunity for constructing a new story-line because of the possibility of developing a collective identity, actually connecting to a group may require a 'getting ready' stage. In other words, simply providing the information about group meetings may be inadequate for some. Rather, a gradual introduction which respects the individual positioning may be more useful. Second, alternative ways of connecting which may be less threatening and less dependent upon individual motivation require exploration. For example, Mrs. Ford relied upon an informal telephone network. Finally, different types of groups may be more useful at different 'stages' for challenging the dominant story line.

For example, a primary focus on education and information may be useful initially as a means toward medicalizing the partner's symptoms. However, if the power of the group rests in its possibilities for promoting a collective identity then a shift from education to ongoing support would be required. Currently the thrust is toward time-limited focused groups interventions (Lavoie, 1995) which may respond to the first set of needs but not the latter; in fact they may sabotage the development of a collective identity by reinforcing a narrowly defined, problem-centred focus to one's situation..

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In summary then, the first story-line positions caring activities as an extension of the marital role and hence private. A first task for Social Work intervention is to begin to challenge some aspects of this story line in order to open the space for difficulties to be interpreted as situational rather than indicative of individual deficiencies. The intent is to legitimize service use as a right. Four strategies have been identified for assisting with this task. These include: examining personal assumptions and beliefs surrounding the responsibilities of the well spouse; developing an alternative language for talking about the situation; re-visioning the notion of caring; and decreasing the isolation common to the experience of living with a memory impaired partner.

The Public Contribution of Caring

At the opposite pole from the above is an alternative story-line which is used to locate caring within the public realm. Theoretically, this story-line begins to recognize the societal contribution that the well spouse is making through his/her role as 'caregiver'.

Simultaneously, it also makes visible societal responsibilities in the provision of this care. In other words, this story-line invites us to reconceptualize our perception of the dichotomy between family care and formal care: With this new vision, community care means everyone assumes some responsibility for providing some of the care.

This story-line has two significant implications for service use. First, it grounds the provision of services as a right rather than a need. Second, it presumes a collaborative relationship between informal and formal service providers in caring for the ill person.

In my study, a number of the participants espoused some belief in this story-line. However, the anger expressed in their personal narratives made clear that generally it was a story-line which in practice received only limited credibility. This discrepancy in vision highlights the impracticality associated with encouraging individuals to articulate a new story-line without challenging the dominant societal story-line upon which services are based. There is after all some accuracy to the familiar adage that `actions speak louder than words'.

The critical task then is to develop services which in fact demonstrate the assumptions underlying the story-line which locates caring as a public responsibility. Two strategies for accomplishing this are identified: redefining the relationship between the informal and formal service providers; and insuring adequate, appropriate services.

Redefining the Relationship

Collaboration implies a reciprocal relationship in which all partners work co-operatively together. Ideally, it requires acknowledging that each partner brings unique

knowledge and skill to the relationship which, when combined, promotes a better 'product' - in this case, higher quality care. The word conjures up images of respect, recognition and mutual need. Although there were isolated examples where participants' described this relational quality with individual service providers, the general experiences of the participants in this study suggest that this was not the norm. Rather, participants described feelings of being patronized and discounted. This finding suggests the need for the relationship between service providers and the well spouse to be redefined.

Perhaps a first step in establishing this `collaborative relationship' is to begin to itemize what each partner actually brings to the relationship. In this study, the importance of the well spouse for preserving the personhood of the ill partner as that person became increasingly unable to do so independently, surfaced repeatedly. For example, participants talked about the intimate connection that enabled them to anticipate their partner's needs, they provided the history to contextualize their partner's actions, and they interpreted the behaviours of even the most seemingly uncommunicative dementia victims in a way that maintained the ill partner's humanity.

In principle, the contributions that the family 'caregiver' can make as a result of his or her unique knowledge of the care-receiver's preferences, values, needs and life history are recognized (e.g.. Lesemann and Martin, 1993). However, in practice, this study suggests that there may be a tendency for service providers to discount this special knowledge, a finding which is consistent with other research (e.g.. Rutman, 1996; Morgan, 1993; Hasselkus, 1988). This results in tensions of ownership over knowledge and a breakdown in communications between health professionals and service providers (Hasselkus, 1988).

> ... when interactions and relationships are focused solely on the visible action component of the situation, the powerful invisible forces that frame the action are ignored and incompatibilities, misunderstandings, and misinterpretations are inevitable...effective collaboration between family and professionals depends not so much on shared tasks and functions as on shared perspectives and understandings of the invisible work of caregiving (Hasselkus, 1988 p.690)

Developing a collaborative relationship then requires recognizing, validating and utilizing the unique expertise that the well spouse brings.

There is a potentially threatening implication associated with this shift. Specifically, it means that health professionals, including Social Workers, are required to relinquish exclusive claims to authority and, paraphrasing Mr. Archer, lower themselves from their self imposed pedestal. This necessitates the development of a radically different lens through which to view the relationship. As part of this process, Fook (1993) suggests that Social Workers need to examine how professional practices and beliefs regarded as normal, desirable or expected may function to maintain the professions' status and/or its dominance over clients.

> The theoretical aspect of this ideology is that professionals are experts who know more than clients about their problem situation and the means to deal with it. In practice this means that they assume a professional, expert role often distancing themselves from clients and in the process distancing clients from the means to rectify their situations. The institutional aspect of this professional ideology is the arrangement whereby professionals act in an entrepreneurial middle-person role,

effectively controlling the means and resources for problem alleviation. (Fook, 1993 p.60-61)

Developing a collaborative relationship means leveling the power differential between the well spouse and service providers. This requires recognizing the expertise that the well spouse brings in relation to his or her situation. However, it means more than this. Specifically, it also involves insuring that the spouse has direct access to adequate resources.

Insuring accessible, adequate services

Professional control over access to services insures the continued power differential between the formal support service providers and informal family caregivers. For example, several participants spoke disparagingly about a newly implemented system for centralizing nursing home placements. While logically this system made sense (and cents?) in terms of simplifying the process, it left several participants feeling powerless in the important decision of selecting an appropriate long-term care facility for their spouse. Similarly, participants identified difficulties in accessing other services related to the perception that they were being discounted. This included problems in convincing the family physician that something was wrong with their partner and contending with rigid eligibility criteria of some services.

Additionally, almost all of the participants commented upon the inadequacy of services to meet their needs. This was related to the amount of assistance provided; respite services for example offered too few hours to be perceived as really helpful. It was also

related to the type of services available; services such as homemaking were frequently seen as taking on a non-problematic aspect of the well partner's experience and making it problematic in order to accommodate the services! Contending with service inadequacies places the well spouse in a double-bind. One must be 'grateful' for what one gets and not complain; anger will earn one a pejorative reputation and may jeopardize existing support. This situation successfully guarantees that services will not be forced to be more responsive to the needs of the family caregivers.

To begin to equalize this power differential, ways of providing services which promote increased accountability to the family are required. One strategy for achieving this that has received some support both in this study and in other research (e.g.. Morris, 1994; 1991/1992; Keefe, 1993; Abel, 1991; Croft, 1986), is to financially fund the 'consumer' - in this case the family caregiver - to directly arrange the services s/he feels are required While it is recognized that for some this might be overwhelming and unhelpful, for others it would instill a feeling of authority in the situation that is currently often lost as public support services 'take over'. Furthermore, it places an expectation upon services to be responsive to the needs of the well spouse rather than assuming that the well spouse will 'make do' with whatever offered; spouse can 'fire' those service providers who do not meet their needs.

Underlying this arrangement are two requirements. First if the assumption is that spouses have a legitimate right to support, then a foundation of services which addresses normative levels of support must be developed. This could include establishing concrete, practical "terms and conditions" for caring and then insuring that services are available to

fulfill this contract (Twigg, 1993). Second, it goes without saying that to be effective, funding must be sufficiently substantial to motivate service providers to be responsive to the well spouses' needs.

I want to be clear that I am not advocating the universal acceptance of the use of the spouse as care-manager. While some spouses may in fact work themselves into a position where they have the knowledge, experience and skill to perform this function, most do not. As Neysmith (1991) notes:

> any potential empowerment or sense of control to the kin carer envisioned by this model has to be weighted against the costs to her [or him] in terms of time and energy (p. 289).

An alternative model could accord 'consultant' status to the professional, for example the Social Worker, who does have the knowledge and connections to effect the required arrangements. In this model the well spouse would be responsible for outlining his or her requirements and it would be the professional's role to develop a plan for most effectively responding to the stated requirements. Depending upon the individual situation, the professional role could range from simply advising regarding potential options to actually implementing and managing a plan. This arrangement honors the expertise of both the professional and the spouse.

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In summary, to this point, I have addressed some implications for Social Work practice associated with two opposing story-lines for locating the structure of caring. One

positions it as an extension of the marital relationship while the other removes the expectation that it will be the sole responsibility of the spouse and recognizes societal responsibility in the situation. When spouses are relying predominantly upon the first story-line there is little room available for sanctioning the use of support, particularly formal services. This is problematic because research has consistently concluded that one individual can not manage the herculean task of assuming full-time responsibility for an individual suffering from a dementia without ultimately damaging his or her own health. To help foster a less pejorative view of support the goal of Social Work intervention in this situation is to assist the spouse to re-envision his or her caring activities using a more public lens. Strategies for accomplishing this have been suggested.

However, there is a problem with this new story-line. Specifically, individuals relying upon it to make sense of their experiences demonstrate that in practice it has only marginal acceptance as a story-line. Structural changes are required to legitimize the assumptions and beliefs being promoted by it. These include redefining the role of the family 'caregiver' within the formal support service system.

As initially noted, this site is not the only one identified as influential for making sense of formal support services. Rather, the story-lines one relies upon to constitute one's psychological orientation also impact meaning. Next, I will examine the implications for intervention associated with psychological orientation. This domain contains two opposing story-lines to account for how one makes sense of one's 'self'. I have entitled these story-lines 'the independent, autonomous self' and the 'relational self'.

The individual, autonomous self

This story-line incorporates the ideology of individualism and autonomy. At the individual level, it fosters a sense of competence and control as central issues in the maintenance of a healthy sense of self. When applied to the experience of living with a memory impaired partner, this story-line makes visible the attack on the well spouses sense of self caused by his or her inability to retain control in the situation. Within this context, the negative meaning that can be associated with the use of formal services as a further example that one has lost control becomes apparent. This story-line does offer some possibility of utilizing services however because it challenges the notions of the selfless carer by introducing a language which sanctions taking care of oneself.

Using this story-line, the importance of fostering the well spouse's sense of control and competence in this situation emerges as a critical Social Work task. Three strategies for accomplishing this are identified: normalizing the experience; reframing the use of support as a means for maintaining control rather than a signifier that control has been lost; and contextualizing professional involvement in order to avoid delegitimizing the well spouse's efforts.

Normalizing the experience

In a variety of ways, all of the participants demonstrated that living with a memory impaired partner resulted in a serious attack on one's sense of competence. This was related to both the loss of control over the situation and, particularly for the women, the personalization of the deteriorating marital relationship. Participants in this study identified

the ease with which this attack on their competence could be interpreted as a personal deficiency. Specifically, the loss of control associated with the process was often perceived as stemming from one's own personal ineptness.

Caring for a memory-impaired partner is a Herculean task that must be named. The intent is to normalize losses of control in relation to both the experience and the relationship with one's spouse as situational rather than a sign of personal weakness or deficiency.

> Oppression becomes psychologized as a pathological entity as the discourse is changed from one of external social context to one of internal structures and distress....Naming is a powerful act; to name an experience or phenomenon as psychological and internal as differentiated from political and social can transform one's relationship to reality in a manner subversive to feminism rather than to patriarchy (Brown, 1993 p. 32-.33)

A therapeutic task then is to prevent problems associated with loss of control over either the situation or the relationship from being internalized. This can be done by challenging the perception of personal deficiency through the process of normalizing the situation. For example, this may include reinforcing the ill spouse's deterioration as a symptom of a disease process rather than a response to the well partner's treatment. Similarly, the Herculean nature of the caregiving task can be named. Support groups may provide an especially viable context for this `consciousness raising'. By identifying and labeling the contradictions and impotency inherent in the situation , the well spouse may be encouraged to normalize their difficulties rather than internalizing them as personal failures.

This then opens up the psychological space to begin recognizing and validating their efforts.

Reframing Support

Because so many of the participants either explicitly expressed or implicitly alluded to the loss of control associated with the use of services, it would seem that this is a topic which requires direct exploration with the well spouse. This could include discussing concerns about loosing control and verbally repositioning service use a means for retaining control.

However, in addition to verbally reframing the use of service concrete opportunities for exercising control must be made. For example, this could include insuring that the well partner has necessary information regarding what services are available and is therefore in a position to determine which services can most adequately respond to his or her needs. Similarly, efforts could be taken to accommodate the well partner's schedule. Perhaps most importantly, participants in this study identified the need for control in selecting who would be providing assistance and other studies have reported similar findings (e.g.. Gwyther, 1994; Morris, 1994; Caserta et al. 1987). Insuring that the well partner exerts control in the decisions surrounding his or her service use has the potential to reinforce the perception of services as a right and not a need.

In considering the idea of promoting individual autonomy in service use, Capitman and Sciegaj (1995) distinguish between different models of autonomy: ideal, real and contextual. Ideal autonomy presumes rational capacity, sufficient knowledge about one's situation and the absence of internal or external constraints. Real autonomy is reduced

autonomy and requires a consideration of an individual's physical, psychosocial and spiritual dimensions. Both of these models are limited by their sole focus on individual meaning of autonomy. In contrast, a third model of autonomy, contextual autonomy, is identified as more relevant to understanding meaningful individual choice within the service delivery system. It recognizes the interplay between the individual and the social/institutional context.

> ...the primary question that contextual autonomy raises for long-term care is: "Given the individual's capacity and circumstances and the options available in this delivery system, are the individual's care choices meaningful and respected by care providers" (Capitman and Sciegaj, 1995 p.534)

I find this concept of contextual autonomy useful. It promotes recognition of the importance of an individualized assessment of the strengths and limitations of the well spouse while simultaneously acknowledging the power of the service delivery system to either aid or impede individual opportunities for meaningful choice.

Contextualizing Professional Involvement

When Mr. Malloy expressed concerns that the high quality of care delivered by the service providers maligned his coping skills, I was alerted to the potential backlash that service use could have in further undermining this sense of competence. Specifically, many of the participants held the expectation that one `should' be able to manage a given situation; requiring assistance, and watching another person handle the situation in a more effective

manner could leave one feeling deficient and/or unable to live up to established standards.

This highlighted for me the need for Social Workers to consciously contextualize their efforts. For example, recognizing that one's response to a particular situation or behaviour are coloured by the overall situation may be useful to address explicitly; in contrast to the spouse the Social Worker does not carry the 24 hour weight of watching one's partner deteriorate. There is a potential for professional counseling and education to erode the caregiver's confidence that must be recognized.

The Relational Self

This story-line posits the importance of relationships for defining and judging one's self; a sense of self is both developed and maintained through one's relationships with others. The assumptions and beliefs of this story-line exerted strong influence in the personal narratives of the women in this study and on the wives in at least one other study (Miller, 1987). This suggests the need for a gender-sensitive approach to intervention since husbands and wives seem to be emphasizing different story-lines for sense-making.

This story-line centres the importance of relationships for influencing the interpretation of the experience of living with a memory impaired partner. In particular, it draws attention to two aspects of the experience which emerged as critical in relation to service use. First, it brings to the forefront the importance of the relationship between the well partner and the ill partner. Second, it elicits recognition of the potential of relationships per se for facilitating support.

Recognizing the power of the ill spouse

For me, one of the most obvious themes to emerge early in this study was the influence of the ill husband in defining the situation. Logically, this was unsurprising; I experienced an `of course' reaction. What was startling however was the realization that in my previous clinical practice I had rarely explicitly addressed the power exerted by this important person.

Recognizing this power has several implications for Social Work practice. First, all of the women highlighted the importance of their husband's cooperation in service planning. While husband's appreciated their wive's co-operation several provided examples to suggest that it was not imperative. In contrast, all of the women in this study identified reluctance to utilize services that were not condoned by their partner. Other studies have reported similar findings (Rudin, 1994; Gwyther, 1994; Miller, 1990; Lawton et. al, 1989). This has been found to be related to a reluctance to acknowledge the ill person's declining decisional capacity (Gwyther, 1994) but also reflects the same desire as that expressed by some of the participants in this study to promote the ill partner's sense of autonomy whenever possible (Rutman, 1996).

This means that Social Workers need to develop new ways for working with the impaired partner rather than focussing solely on the well spouse for decisions. Recognizing the deteriorating capacity for decision-making associated with a dementia this task is formidable. It requires searching for ways to frame support with the ill spouse that will assume his or her dignity and be perceived as least threatening. Mrs. Knight for example, found that when she presented the use of service as something her husband could do for her,

as opposed to focussing on her husband's deficits, her husband responded more favourably to the use of services.

Additionally, service providers may need to reposition the use of formal support for the well spouse in order to promote acceptability. A relational perspective suggests that women tend to be `other' directed; they may have difficulty recognizing their own needs and, if they do, self directed behavior may be pejoratively viewed as selfish. This internalization could deter help seeking. For example, women may feel a lack of entitlement to formal supports (Aronson, 1992) or may prefer to bear the burden in silence to avoid the risk of being seen as selfish or uncaring (Neysmith, 1991). Bearing in mind the Social Work axiom to `begin where the client is', service providers may consider initially positioning the use of support to focus on benefits to the husband. For example, the perception of service use as selfish may be countered by highlighting the wife's need to care for herself so that she remains well enough to care for her husband; this for example was the rationale used by Mrs. Cook which ultimately fostered the use of services. Formal support services may not offer a panacea, but they have *no* potential to help unless they can gain entry.

Listening to the women's stories alerted me to the physical dangers associated with ignoring the significant power wielded by the husband. Four of the six women in this study expressed fear of physical aggression and this potential for physical violence directed at wife caregivers is beginning to be supported by other research. For example, Bartlett (1994) reported "unexpectedly high" incidences of husband's with dementia being physically aggressive with their wives and Lyon's (1996) study of wives who had institutionalized

their husbands found that two of the three wives who participated in her small study indicated concerns about violence prior to placement. Service providers then, must be sensitive to power issues. Specifically, there is an implicit assumption that women can, and should, assume control over the decisions affecting their memory-impaired husbands. This presumption ignores both the historical and physical sources of power within the relationship. This is a critical oversight. Issues of power must be explicitly addressed. For example, possible threats to the wife's safety when dealing with a husband who suffers from a dementia require exploration. Similarly, the potential impact on a wife's sense of self when placed in the position of defying her husband with her decisions is an issue which warrants attention. Failure to recognize power issues could result in service providers inadvertently placing women in a no win situation where they feel caught in the middle; trying to respond to health professionals instructions and still meet the demands of the care-receiver (Hasselkus, 1988).

In addition to his power in defining the situation, this study also raised my awareness regarding the influence of the ill husband in his wife's definition of her self. Social Workers may need to be especially sensitive to the potential of professionals to delegitimize the efforts of the well spouse when dealing with wives whose primary identity is grounded in the caregiving activities. For example, Mrs. Cook succinctly addressed her lack of being outside the caregiving role and the stories of several other participants identified the void that would be left without their caregiving activities. If caregiving assumes preeminence as a primary means for affirming existence, then the well spouse may be quite protective of this role. This means that formal support providers could be perceived as

threatening unless they are able to explicitly support the wife's status as the expert within her particular situation.

Given the importance of the connection with one's husband, it is not surprising a tension arose between personally externalizing one's partner's condition while simultaneously insuring that others did not. For example, it might be acceptable for the well spouse to reference one's partner as `the patient' but offense could be taken should an `outsider', for example a service professional, do so. This brings the risks associated with medicalization as a process which fosters the depersonalization of the ill partner, to the forefront. The wife must continually 'reinvent her partner' (Rossiter, 1996 personal communication) in order to maintain his personhood and her relationship with him, while simultaneously trying to distance herself.

Building Relationships

This story line which organizes psychological orientation as relational, raises questions regarding the appropriateness of the current thrust of intervention generally directed toward caregivers, particularly for women. Specifically, this story-line emphasizes the importance of relationships for enhancing self esteem for women and identifies the detrimental impact on well-being of the deteriorating relationship with one's partner - as opposed to the physical task of caregiving. Yet, little attention has been given to responding to relational needs within the formal service delivery system. As noted by Baines et al. (1992) caring is essential to keeping the human enterprise going yet it remains largely invisible in the delivery of social services (p.40) Rather, for caregivers, support has most

frequently been framed in instrumental terms. Programs such as respite for example, are created with the expressed goal of decreasing the physical burden of caregivers. While in no way diminishing the importance of a physical break, this focus of formal support may be founded on premises that overlook the particular needs of wife caregivers. An emphasis on building relationships may be more consistent with the story-line which fosters a sense of self as relational. In this study, the importance of the relationship between the well spouse and the service provider clearly emerged as a more important consideration than the appraisal of task management: `Successful` service providers could be recognized by the personal and friendly way they were regarded and not necessarily by the quality of their work.

As previously noted, a sense of isolation was a universal experience of all of the participants. Given this context it is not surprising that there are few opportunities to develop or maintain a sense of self outside of the caregiving relationship. Particularly with women, an important function of support services may be to provide an alternative relational context through which to experience one's self. In other words, services may attain their status as `supportive' because of their potential to provide a positive relational context within which women can experience themselves. For example, respite care has been framed as a means for giving caregivers a physical break; for women it is conceivable that one of its primary benefits is the time and opportunity to either reconnect with friends and family or to develop a new connection with the service provider. Similarly, the relationship with a community health professional may be a more powerful support than the concrete tasks that are done during his/her visit. Increasingly, the importance of the relationship between service recipients and providers is being recognized (e.g.. Woodruff and Applebaum, 1996;

Barer, 1992; Eustis and Rose-Fischer, 1991).

Relationships are a source of power and effectiveness (Lazzari, Ford and Haughey, 1996 p.198). However, in order to harness this potential support, attention to relationship building is required. At the most basic level this requires insuring consistent service providers and sanctioning the time spent developing relationships. It also suggests the need for active outreach initiated by the `community', for example a Social Worker, as early in the process as possible so that the well spouse has the opportunity to develop a relationship with at least one person who can be accessed in times of crisis. This introduction could be orchestrated in co-operation with family physicians since seeking medical assistance early in the process appears to be a typical first response to difficulties and research suggests that the family caregiver may be most receptive to help immediately following diagnosis (Karlin and Bell, 1992). This would have the added benefit of promoting an appropriate response to the well spouse's need for information at this critical time. Once connected, periodic contact could be maintained to afford the opportunity for the well spouse and Social Worker to become familiar with one another; this might consist of no more than a regular telephone contact focused on insuring that the well spouse is aware that s/he is not alone.

Summary

In this preceding sections I have begun to address the practice implications that emerged out of this study for me. There are four key themes associated with these implications. First, the importance of the dominant discourse on caring which positions caring activities as a natural extension of the marital relationship, and hence private, is

recognized. I see this as a story-line which will undoubtedly continue to exert considerable strength. However, recognizing that the majority of families will undoubtedly not wish to entirely discontinue their involvement in their care, consistent with other researchers (e.g.. Rutman, 1996; Aronson, 1991) I am advocating the creation of public policies and practices which respond to the needs of spouses by insuring that support is available to them as a right. I have suggested strategies for assisting spouses to reconceptualize their rights and responsibilities to their partner, and I have proposed structural changes in the provision of formal support which are required to convey these rights. Additionally, the impact of the experience of living with a memory impaired partner has been recognized as precipitating a loss of control over the situation and in the marital relationship. Strategies for combating a tendency to internalize these difficulties have been identified: it is important to move the focus from the individual as the problematic to the situation. Finally, I have examined some of the implications associated with Social Work intervention when the story-line that organizes one's psychological orientation as relationally based is used as an interpretive repertoire for this experience of living with a memory impaired partner.

In developing these suggestions I remain aware of the gaps in knowledge and the questions that have resulted from this study. The next section will briefly identify directions for future research.

AREAS FOR FUTURE RESEARCH

The importance of constructing a social identity as `caregiver' on the use of formal

support services is an important finding of this study. Although participants provided some insight regarding how this might come about, this insight is retrospective and wrought with gaps. In order to begin to facilitate this process, further exploration into this process would be useful.

An unexpected finding of this research was the high prevalence of physical violence directed toward the women. Specifically, two of the well wives acknowledged physical abuse, two more identified fear that their husbands would be violent, and incidents of violence directed at three of the ill wives were identified. In other words in 50% of the couples interviewed issues of violence toward the wife were raised; I recognize that this small, purposive sample can not be used to generalize or establish statistical significance, but it is worth noting that this figure is considerably higher than prevalence rate of 4% found in a recent Canadian study (Podnieks, 1990). Moreover, that it was predominantly women not men that experienced physical aggression - irrespective of their role within the caregiver/care-recipient dyad - would tend to raise questions about the emphasis on caregiver stress rather than gender as a precipitating factor associated with abuse. Rather, the issue of elder abuse has tended to be neutralized in current research and the need for a feminist analysis is identified (Whittaker, 1995). Specifically, the implications of living in a patriarchal family system on the experience of the living in a marital relationship where one partner suffers from a dementia, requires further examination.

Throughout this study I have made an implicit assumption that formal service use has the potential to positively assist spouses during the experience of living with a cognitively deteriorating partner. This assumption however is not well grounded in the literature.

Further research and `experimentation' with various types and ways of developing services is required to determine how service use can exert a beneficial impact and in what circumstances..

Moreover, this research has re-emphasized the role of the marital contract for formalizing the caring relationship. However, many longstanding relationships do not fit this traditional notion of `family'. Research exploring the experiences of individuals in less traditional types of relationships who are living with a partner who suffers from a dementia is required.

Finally, an obvious limitation to this study is its inability to reflect on issues of race and class. All of the participants in this study were white, middle-class individuals. Although the general principle arising from this research regarding the importance of identifying the story-lines that are being used to construct one's personal narratives remains relevent, the specific relevence of the four story-lines that I uncovered in this project for caregivers of other races, cultural backgrounds and classes remains unclear.

CHAPTER 9

CONCLUSION

I recently read a thesis which concluded with an `anti-conclusion' rather than a conclusion (Ross, 1996). This fits much better with my understanding of my process than to be attempting to write something that leaves the impression that this is a finished, finite piece of work. Rather for me, both the frustration and the excitement is that for every new insight that emerged, another question was also raised. I am left with as many questions as when I began, they are simply different. This means that each time I read this document, I find gaps into which I want to delve deeper. Notwithstanding this, I will attempt to pull this thesis together in a way that it can, at least temporarily, be seen as `complete'.

This thesis has been about three overlapping issues for me. Substantively, it has been about developing better understanding of the personal experience of living with a memory-impaired partner and exploring how this experience interfaces with the use of formal support services. Based on my professional experience I was aware of diverging `realities' between what the literature suggested was happening with spouses living with a memory-impaired partner and what these spouses seemed to be suggesting their experience was. I started by wanting to better understand their experience from their perspective. My goal was to contribute to the practice literature ideas that would assist Social Workers to work more effectively with this population.

However, there has been a second level to this study. Specifically, it has been about learning qualitative research methods and beginning to recognize both the limits and capabilities of these methods. I began with a simplistic but thorough understanding of naturalistic inquiry as proposed by Lincoln and Guba (1985). I had a clear agenda - to give voice to a group of participants who belonged to a population whose voices were not being heard - and had clearly established the ways that I would ensure the `trustworthiness' of my findings. In good faith I set off. However, problems emerged when I began to try to make sense of what the participants in this study had to say about their experience. Specifically, I grappled with each person's transcript and began to pull out the main themes associated with service use. At this point in the process, I could classify the meanings associated with service use into clear discrete categories: for example, service use as a sign of weakness, service use as a form of respite, service use as signifying the `end of the road'... I was even able to compile a list of the different meanings that people assigned to the use of services and group these according to rules for inclusion or exclusion. The problem however, was that I had no way of accounting for the fact that each person's `meaning' could fall into several, sometimes conflicting categories. It was here that I quite consciously left behind some of the more traditional qualitative research methods and moved into more critical perspectives.

My attention turned to trying to make sense of these contradictions. At this point, I began to focus on the importance of language for both constructing one's `reality' but also for exposing hidden assumptions and beliefs that were being used in this construction. By reading beyond the words, I began to develop a conceptual model that could help make sense of the complexity associated with assigning meaning. This model helped me organize my

thinking. However, it also created a problem - I could no longer claim to be `telling the story' of the participants. I was now telling my story.

Hence, for me, this project has also been about ethical dilemmas. I have struggled to integrate my reality that I am here in my work both out of necessity - I cannot `not be present' - as well as out of desire - I want to be heard! - with my conviction that I do not want to appropriate the experiences of the participants. Paths that seemed so clear to me when I began this project have turned out to be part of a maze. I don't feel that I have yet found the centre.

What do I feel I have established? I believe I have begun to expose the complexities in the interface between the private experience of living with a memory-impaired partner and the public experience of using formal support services. Personally, I have become much more conscious of the power of hidden assumptions and beliefs in constructing both individual meaning and social practices. I have named the dominant discourse on caring as oppressive and have promoted an alternative discourse for understanding the experience of living with a memory-impaired partner that is more conducive to the use of formal support. I have explicated how gendered interpretations of this experience might be produced. Finally, I have attempted to articulate strategies for promoting more responsive, less oppressive support for the well spouse. Specifically, I have identified the importance of identifying and addressing the multiple and sometimes contradictory story-lines that can be used to construct one's own personal narrative as an important aspect of intervention.

What have I not established? I have no doubt that there are other levels of understanding of which I have only begun to scratch the surface. I do not question that there

remain other discourses that are influencing the meaning making associated with service use that I have not even begun to uncover. In this sense, my project remains contingent and incomplete.

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APPENDIX A - LETTER OF ETHICAL CONSENT

Wilfrid Laurier University

Founded 1911

August 13, 1993

Ms. Deborah O'Connor
79 Withrow Avenue
Toronto, Ontario
M4K 1C8

Dear Ms. O'Connor:

Re: DSW proposal entitled "Experience of Living with Memory-Impaired Spouse"

The Ethics Committee of Wilfrid Laurier University has reviewed the above proposal and determined that the proposal is ethically sound, subject to the Research Office receiving a copy of your forms incorporating suggested revisions.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please contact me as soon as possible and before the changes are put into place.

Yours sincerely,

Michael D. Moore, PhD
Associate Director of Research, and
Chairperson, WLU Ethics Committee

MDM/jb

cc: M. Laurence, Advisor

The Director: University Research
Wilfrid Laurier University, Waterloo, Ontario, Canada N2L 3C5 (519) 884-1970 Fax: (519) 886-9351

APPENDIX B: CONSENT TO PARTICIPATE

CONSENT TO PARTICIPATE

I, agree to participate in the study being conducted by Deborah O'Connor under the supervision of Dr. Martha K. Laurence (519-884-1970). This study is focused on exploring the experiences of individuals living with a spouse who suffers from memory impairment.

I understand that:

a) My participation in this research is voluntary;
b) I have the right to terminate my involvement at any time;
c) I have the right to refuse to answer any questions with which I feel uncomfortable;

Moreover, it is also my understanding that:

d) There are no known risks associated with participating in this study;
e) There are no direct personal benefits associated with participation.

Finally, I further understand that:

f) All information collected for the purpose of this study will be treated in strictest confidence;
g) Any reports/papers, either published or unpublished, that result from this research will preserve codes of confidentiality and anonymity;
h) All interview transcripts will be confidential and appropriate care taken to safeguard them by securing them in a safe place.
i) All records will be destroyed within an agreed upon time period.

_____ _____

Name (please print) **Signature**

_____

Date

CONSENT TO AUDIOTAPE

I give permission for my interviews to be audiotaped. I understand that I have the right to turn off the tape recorder at any time during the interview.

_____

Signature